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ABSTRACT

The conference reported in this document had three aims: to initiate dialogue on furthering the goals of the Americans with Disabilities Act of 1990 (ADA) through disability policy research; to identify the resources and infrastructures available to enhance the process; and to articulate steps that can be taken to monitor implementation of the Act. The conference included plenary sessions on the following issues: disability research and enforcement of the ADA, putting research to work for the realization of the goals of the ADA from the perspectives of the disability community and of minorities and other underserved populations, shaping an interdisciplinary field of disability studies, strategies for adopting a common nomenclature, research strategies for statistics using survey data, the role of quantitative and qualitative methodologies, research strategies for monitoring the ADA, and future trends in disability policy research. Eight smaller "breakout" sessions examined the topics of equality of opportunity, full participation, independent living, economic self-sufficiency, issues related to special populations, emerging issues, building a disability studies discipline, and creating a common nomenclature and classification. The document contains presentations, discussion, reports from the breakout sessions, and recommendations. Appendixes contain the conference agenda, participant and speaker lists, and a description of the National Council on Disability. (JDD)

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National
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Furthering the Goals of the Americans with Disabilities Act Through Disability Policy Research in the 1990s

Summary of Proceedings

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Washington, D.C.
December 7-9, 1992

Co-Sponsored by the National Council on Disability and the National Institute on Disability and Rehabilitation Research

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on Disability

Furthering the Goals of the Americans with Disabilities Act Through Disability Policy Research in the 1990s

Summary of Proceedings

Washington, D.C.
December 7-9, 1992

Prepared by: Walcoff & Associates

Co-Sponsored by the National Council on Disability and the National Institute on Disability and Rehabilitation Research

Furthering the Goals of the Americans with Disabilities Act Through Disability Policy Research in the 1990s

Summary of Proceedings

Publication Date: December 31, 1993

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NATIONAL COUNCIL ON DISABILITY

An independent federal agency working with the President and the Congress to increase the inclusion, independence, and empowerment of all Americans with disabilities.

Letter of Transmittal

December 31, 1993

The President
The White House
Washington, DC 20500

Dear Mr. President:

I am pleased to provide you with the National Council on Disability's report entitled *Furthering the Goals of the ADA Through Disability Policy Research in the 1990s: Summary of Proceedings.*

As the federal agency that initially proposed the Americans with Disabilities Act of 1990 (ADA), the National Council feels a particular obligation to ensure that the ADA is fully and successfully implemented. With this ongoing effort in mind, the Council conducted a national conference on December 7–9, 1992, designed to initiate dialogue on furthering the goals of the ADA through disability policy research, to identify the resources and infrastructures available to enhance the process, and to articulate steps that can be taken to monitor the implementation of the Act.

The conference, which was cosponsored by the National Council on Disability and the National Institute on Disability and Rehabilitation Research, drew nearly 200 participants representing the community of people with disabilities, senior administrators, and accomplished academicians. Beyond the many recommendations detailed in the report, we are most pleased to inform you that the process underlying the conference was one wherein we brought constituencies who would be directly affected by the outcome into the discussion as equal participants from the beginning. We believe this reflects your "putting people first" approach to government and hope that you will agree with us that the recommendations resulting from this process are responsive to the needs of all Americans with disabilities. Once again, thank you for this opportunity to be of service.

Sincerely,

John A. Gannon

John A. Gannon
Acting Chairperson

(The same letter of transmittal was sent to the President Pro Tempore of the Senate and the Speaker of the House.)

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Executive Summary

The landmark Americans with Disabilities Act of 1990 (ADA) signaled a new era in protecting the civil rights of persons with disabilities. Since the passage of the ADA, much attention has been focused on assessing the ADA's impact and on broader issues of disability policy. Research, utilizing both quantitative and qualitative methodologies, is a crucial tool for assessing the current status of the implementation of the ADA and for monitoring the effects of the ADA. However, the young and rapidly evolving field of disability policy research has been hampered by inadequate data and by lack of consensus about the most appropriate ways to study and assess disability policy.

On December 7–9, 1992, the National Council on Disability and the National Institute on Disability and Rehabilitation Research (NIDRR) cosponsored a conference entitled *Furthering the Goals of the Americans with Disabilities Act Through Disability Policy Research in the 1990s* in Washington, DC. The main goals of the conference were (a) to initiate dialogue on furthering the goals of the ADA through disability policy research, (b) to identify the resources and infrastructures available to enhance the process, and (c) to articulate steps that can be taken to foster disability policy research. Conference sponsors also hoped to make progress in establishing a research agenda for the 1990s that would be responsive to the goals of the ADA. Nearly 200 participants attended all or part of the conference.

The conference included plenary sessions on disability research and enforcement of the ADA; putting research to work for the realization of the goals of the ADA from the perspectives of the disability community and of minorities and other underserved populations; shaping an interdisciplinary field of disability studies responsive to the goals of the ADA; strategies for adopting a common nomenclature that is responsive to the goals of the ADA; research strategies for statistics using survey data; the role of quantitative and qualitative methodologies; research strategies for monitoring the ADA; and future trends in disability policy research.

Conference attendees also participated in eight smaller "breakout" sessions. These sessions examined topics such as equality of opportunity, full participation, independent living, economic self-sufficiency, issues related to special populations, emerging issues, building a disability studies discipline, and creating a common nomenclature and classification. The discussions of each breakout session were reported to all conference attendees during later plenary sessions.

Participants in the conference engaged in dialogue on many issues. Some of these issues, such as full participation of persons with disabilities in research, the most effective mix of qualitative and quantitative research approaches, and use of a common nomenclature, were not resolved. Nevertheless, conference participants provided guidance on building infrastructure and establishing priorities for future disability policy research.

In terms of infrastructure, greater coordination among federal agencies concerned with disability policy is clearly needed. Additionally, the efforts of NIDRR's Interagency Committee on Disability Statistics, which unites data producers and consumers within the federal government, must be supported and enhanced. Other relevant interagency committees involved in examining aging and health issues, in which disability can play a role, must be encouraged to make disability a consideration in *all* major federal policy decisions.

In terms of concrete suggestions to foster disability policy research in the 1990s, conference participants suggested some immediate steps that will have an impact in the short term. These steps include establishing a set of disability indicators; continuing study of the World Health Organization's International Classification of Impairments, Disabilities, and

Handicaps; and ensuring funding for the 1993–94 Disability Supplement to the Federal Census.

Over the long term, conference participants recommended the following actions: involving persons with disabilities (including members of special populations) in the research process; developing positive measures of functional capacity and accommodation rather than relying on existing medical models; disseminating information in formats that policy makers can use; developing ways to integrate qualitative and quantitative research methodologies; improving assistive technologies; improving health insurance coverage for persons with disabilities; and continuing to develop the field of disability policy.

Section I: Proceedings

Opening Remarks

Speakers: **Sandra Swift Parrino,** Chairperson, National Council on Disability

William E. McLaughlin, Acting Director, National Institute on Disability and Rehabilitation Research

Sandra Swift Parrino, Chairperson, National Council on Disability

My name is Sandra Parrino, and I'd like to welcome you to the conference this morning. I am here as chairperson of the National Council on Disability (NCD). I'm happy to say that there are several members and staff of the National Council with us today. We're very pleased you could find the time this very busy holiday season to join us.

I'd like to begin by thanking the National Institute on Disability and Rehabilitation Research (NIDRR) of the United States Department of Education for their support of this conference. Mr. Bill McLaughlin, who is the acting director of NIDRR, is representing the agency today.

The idea for this conference came from a conversation that I had with one of our distinguished presenters over a year ago at a meeting of the American Public Health Association in Atlanta. Dr. Mitchell LaPlante of the University of California at San Francisco approached me to talk about some of the problems he repeatedly encountered in conducting his research. After a number of discussions, we conceptualized the idea for this conference. So I would like to give Mitch credit for initiating what I believe will be a landmark conference and the beginning of some important national and international initiatives.

After my discussions with Mitch, I approached Dr. Bill Graves, the former director of NIDRR, to discuss how we might join forces to promote disability policy research. We agreed that a joint conference was a good place to begin. So, a year and many memos later, here we are.

This conference today was generated from concern about the future of disability policy. The enactment of the landmark Americans with Disabilities Act (ADA) was the beginning of a new era for disability policy. It also marks the end of an era. The era that is ending is one characterized by ideals, enthusiasm, and determination, and a notable lack of data. The era that is beginning must continue to be inspired by ideals, enthusiasm, and determination, but it must be supported by a database.

The post-ADA issues we struggle with in disability policy demand database information: personal assistance, health insurance, technology, productivity in the workplace. We must have solid information to provide to decision makers as they are confronted with policy choices.

One of the many contributions of the ADA is the establishment of national goals for individuals with disabilities. For the first time in our nation's history, our disability policy has overarching goals. These goals are equal opportunity, full participation, independent living, and economic self-sufficiency. These goals are big promises to Americans with disabilities; promises the provisions of the ADA alone cannot meet.

Consider the area of employment. Today, about 13 million Americans with disabilities are jobless. About 28 percent of all disabled people live in poverty, and another 50 percent are near-poor. While discrimination is surely a culprit in this joblessness and poverty, so are lack of education and job skills and access to personal assistance. The ADA will not provide education and job skills and personal assistance for people with disabilities. While we have these laudable goals in the ADA, we still have a system which largely promotes dependence.

The costs of supporting people with disabilities have skyrocketed over the past 20 years. Although the federal government does not compile an annual accounting of private and public disability expenditures, economists at Rutgers University have estimated that expenditures to provide people with work disabilities with a cash income, medical care, and other services rose 300 percent between 1970 and 1986 to a whopping $160 billion. These costs will only grow over the next 20 years as the baby-boom generation ages and acquires disabilities in increasing numbers.

So, how are we going to make these billions of dollars promote independence, rather than dependence; working, rather than not working; living in the community, rather than living in institutions? How are we going to put our money behind our goals?

New policies in the areas of health insurance, personal assistance services, and assistive technology are required. We need data and analysis to promote these desperately needed new initiatives. We can't ask policy makers to mandate comprehensive personal assistance services just because it's a good idea. We have to be able to demonstrate its effectiveness and its payoff. We have to mobilize research skills and results to support our goals for individuals with disabilities.

And how are our disability policies of the future going to address minorities with disabilities? Minorities with disabilities now experience dual discrimination. They are more likely to be poor and unemployed than their white counterparts with disabilities. Minorities are at greater risk for developing disabilities and are overrepresented in the population of persons with disabilities. We have got to put our research to work to address this injustice.

We also have to look toward generic programs to address the needs of people with disabilities, not just disability-specific programs. Vocational rehabilitation provides important services to people with disabilities. But what about the Job Corps and initiatives generated under Job Training 2000? What about America 2000 in Education, and Healthy People 2000, initiated by the Department of Health and Human Services? The initiatives developed in the area of health care reform will provide critical opportunities to ensure that Americans with disabilities are part of the new generic policies, not an afterthought. We must be at the table, with our goals, our values, our determination, and our research.

The enactment of the ADA has created important international opportunities as well. Just as disability policy offers important bipartisan opportunities in domestic policy, so it can be a strong area of mutual agreement in international policy, for the ADA embodies many of the principles articulated in the United Nations World Program of Action for People with Disabilities. Many countries, both developing and industrialized, are watching closely as we implement the ADA. They want to know if this landmark legislation really improves the lives of people with disabilities.

How will we know the answer to this question? How will we be able to share what we learn with our colleagues from abroad? We have no mechanism in place to determine the impact of the ADA. We don't know the employment rate for people with different disabilities in different sectors of the workplace. We don't know how the ADA is affecting the workplace. And if we did know, we probably couldn't share our knowledge with other countries in meaningful ways, since we don't adhere to the international disability classification scheme, the International Classification of Impairments, Disabilities, and Handicaps (ICIDH).

The United States needs to take an active role in working toward worldwide standardization of the international classifications. This is essential in order to share our information with others and meaningfully compare experiences of other nations with ours. To exchange information about policies and their impacts, we must have data. One of the goals of this conference is to further the participation of the United States in the utilization of this international classification scheme. We will hear more about that in Session 4 of this conference.

We have three goals for this conference today. The first is to initiate a dialog between researchers, people with disabilities and their advocates, and policy makers about how disability policy research can facilitate meeting the goals of the ADA. The second is to consider what resources and infrastructure are necessary so that the needed disability policy research can take place. The third is to articulate steps that should be taken to generate the resources and infrastructure we need.

We have asked our presenters to examine these questions from their various fields and perspectives. By the end of the conference, we hope to have a clear sense of how to proceed from here.

So, once again, on behalf of the National Council on Disability, I welcome you to the conference. I would like to extend a special welcome to the graduate students who are here with us for the conference. We hope that the presentations you hear and the conversations you have will be an inspiration to your future careers. I encourage all of you here today to take advantage of the lunch periods and informal times to talk in depth with each other, and I look forward to having the opportunity to talk informally with you as well.

William McLaughlin, Acting Director of the National Institute on Disability and Rehabilitation Research (NIDRR)

Let me give you an idea of what we are up to at NIDRR at the moment and give you a reference to your conference here. We have 32 staffers, which I think is pretty well known. We are a small group; our current budget is 102 million dollars, 68.7 percent of which goes to research and 34.1 percent to state technology assistance grants. We have 44 published priorities currently in competition. I won't read all 44 of them, but in terms of headings in the medical and comprehensive rehabilitation area, we have 12 priorities and the first of those came out, I believe, on Friday. There are 14 in the medical environment. In the psychosocial and vocational rehabilitation area, our first group has 14 priorities and there is a second group with 5 priorities. We have in the research and demonstration project area 2 priorities published, the first of those in family, psychosocial, and transitional issues of children and youth with epilepsy and model systems for burn injury rehabilitation. Then we have 10 rehabilitation engineering center priorities and we believe those to be published momentarily. When you add all that up, it means that we will be holding approximately 40 competitions in the next few months.

We've just completed the field-initiated research competition with approximately 150 applications and will be dealing with the prefunding aspect of that competition in about another 30 days. With the major centers involved in the research environment affected by NIDRR's funding, I discovered that the expiration date of these 5-year centers and the competition date on which we were going to be publishing were badly out of sync, that is, 23 of these centers would be running out of funding by the end of January and we would not be concluding competitions and making new awards until sometime around April, May, or June.

So I was able to talk with a number of lawyers in the department who will be providing supplemental funding for a significant number of those centers to engage in research dissemination, particularly in reference to the way the reauthorization reads and with an effort to capture what those 5-year centers have achieved in alternative formats and in a widely expanded effort to learn what they have learned. That enabled us to overcome what we think was a major administrative hurdle. We will be holding what we hope will be an equitable competition and by June or thereabouts we hope to know which combinations of the existing centers will be successful competitors.

We have 42 states currently engaged in state technology assistance program activities and during the noon hour today, I will go over to the Mayflower Hotel where they are meeting. I think all of you know that we also have 10 ADA-based regional disability and business technical centers.

As far as this particular conference is concerned, I looked at your themes and your topics, building bridges through research which lead to employment, access, inclusion, and independence, a philosophy of consumer participation, consultation and guidance in priorities and research practices. On December 14, I am pulling a group together, which Bill Graves started on September 13 to look at this whole question of consumer involvement in the research process and the constituency involvement. We're taking a very serious look at that and may well be moving Sandra to our questions of policy as it relates to consumer world and involvement in the research activity. Without question, our goal is an accurate, efficient, and effective use of research resources, with an understanding of the many disciplines and parties involved.

I have the responsibility at the moment, along with the Assistant Secretary, for establishing our 1994 priorities. We're very close to a fairly comprehensive list for 1994. But you'll find in the federal cycle of events when you have a major competition, as we do this year for many of our major centers, and then you move to the next year with your priorities and then you try to equate the funding to the priority picture you have going—big awards going this year, a lot of new centers—and then where do you find yourself in moving toward the next year's priorities? So we're working at that with an efficiency in mind and, hopefully, application of the money.

I was particularly intrigued with Sandra's remarks and your agenda, and we want to support the finest and statistically sound reporting with regard to data utilization. The interagency committee on disability research has had off and on years over the decade. We've identified that as one of the problems for the incoming administration to see how this coordinating law that we're charged with can be more effective. For the last several years, there has been a subcommittee on statistics and they have been a very outstanding group, so I think there are bodies of people out there ready to go to work on recommendations that you'll be making.

My final comment is that the conference will assist NIDRR and whomever and however the leadership is determined in the months to come. I am looking forward to our implementation of the recent reauthorization of Title II. The amendments to our previous mission enhance the role of dissemination and full utilization of promising research results. I am a former teacher and school administrator, and the one thing that I talked to the Board of Education about quite frequently was research dedication at the elementary and the secondary levels. It was a question of making research practical, making it apply, and making it fit the needs of those individuals who were in our classroom on that day. The same model exists today, and that's putting research into practice and the new law calls for us to work even more so on that.

Our interagency coordination responsibilities bring us up with many partnerships and, of course, the National Council on Disability is important in that whole sequence of events. I wish you well. I found the past 60 days as Acting Director at NIDRR a tremendous privilege because I have met an extraordinarily fine group of people here in Washington. So good luck, and work hard.

Session I

Keynote Address: "Disability Research and Enforcement of the Americans with Disabilities Act"

Speaker: **John R. Dunne,** Assistant Attorney General, Department of Justice, Civil Rights Division

I am delighted to be here with you today to discuss what was described by President Bush as perhaps the single most important civil rights legislation of the past quarter-century—the landmark Americans with Disabilities Act. I am confident that the ADA, which promises to open up the mainstream—and the main streets—of American life to full participation by individuals with disabilities, will be of great interest for many years to those involved in the thought challenging field of disability research.

Through the elimination of barriers in government, the workplace, and the marketplace, the ADA will promote productive, independent living for persons with disabilities and will enable society, at large, to fully benefit from their skills, their talents, and their dedication. With labor shortages of skilled workers looming at the end of this century, and fierce competition in the international economy, America must tap the human potential of all of its citizens. The ADA will ensure that individuals with disabilities will have the opportunity to make their full contribution to American life and reap its full rewards as well.

President Bush was a stalwart advocate of the ADA right from its very inception. As Vice President, and then as President, he vigorously advocated comprehensive civil rights protections for individuals with disabilities. At the same time, the President is also committed to economic growth and has worked tirelessly to promote America's economic competitiveness. The ADA, by striking a balance between these competing but not irreconcilable interests, splendidly accomplishes both goals. With the administration's support and guidance, Congress was able to fashion a law that protects the civil rights of individuals with disabilities, and at the same time recognizes the legitimate concerns of government agencies and businesses.

While the ADA may properly be described as "revolutionary," it was not without precedent, one with which most of you are familiar. In 1973, Congress passed Section 504 of the Rehabilitation Act which, for the first time, recognized the right of individuals with disabilities to participate equally in programs, such as education, health care, and job training, which received support from the federal government. The Rehabilitation Act and related legislation were extremely successful, particularly in the area of public elementary and secondary education, so that today, integrated, mainstream education is the norm for children with disabilities in public schools.

By the late 1980s, the children of this first wave of the disability rights revolution reached the end of their schooling and began to seek entry into the labor market. It soon became apparent, however, that barriers—legal, physical, and attitudinal—which continued to exist throughout society would have to fall if the educational investment in these children was not to be wasted. The National Council on Disability, of course, took the lead in identifying this problem, and in its 1986 report *Toward Independence*, recommended that Congress adopt comprehensive civil rights legislation to attack these remaining barriers to the full participation of individuals with disabilities in the mainstream of American life. Only 4 years later, in no small part due to the extraordinary leadership of Sandra Parrino and the NCD, the ADA became a reality.

You have asked me to share my views on the relationship of the ADA to the vital field of disability research. Appropriate research can form the basis for the adoption of successful policies that will directly meet the needs of people with disabilities and of entities that have responsibilities under the law. Given the federal government's limited fiscal resources, we should direct our research efforts to areas of inquiry that will be of immediate value in the betterment of the lives of people with disabilities.

There are a series of initiatives currently in progress and to which many of you are making invaluable contributions through your support and active involvement. I know that many of you are aware of, and may well be involved with, the study of the implementation of the ADA that the Government Accounting Office is currently conducting. Presently focusing on public accommodations, the study will ultimately provide us with information that will allow us to gauge our progress in the implementation of the ADA's requirements in employment and telecommunications.

One of our cohosts today, the National Council on Disability, has established "ADA Watch" to monitor the ADA implementation nationwide and disseminate information on innovative ways that public and private organizations can comply with their ADA requirements.

In addition, our other cohost, the National Institute on Disability and Rehabilitation Research, has also recently awarded a grant to Suffolk University in Massachusetts, along with the Shriver Center, Children's Hospital, Boston University, and the World Institute on Disability to, among other things, identify and publicize exemplary implementation programs under the ADA. We hope that the results of this study will prove useful in furthering acceptance of the ADA's lofty goals.

In addition to these long-term studies, there are also valuable research initiatives in progress within the Department of the Interior, the Office of Technology Assessment, and in numerous other public and private organizations throughout the country.

There remain, however, several critical areas that have been neglected up until now, and towards which we should focus our research efforts in the upcoming years. These areas include litigation monitoring, policy development, education, and technology.

Presently, there is no mechanism in place to track and monitor cases related to the ADA as they make their way through the courts. Court reporter publications are geared toward reported opinions and therefore fail to report on most of the litigation that is actually occurring. Early knowledge of pending cases will assist the Department of Justice in assessing the possibility of intervention and amicus participation. A compilation of all pending cases would also provide a valuable tool to gauge which issues under the ADA are proving to be the most contentious and may require clarification through additional policy guidance. Further, this type of systematic monitoring would verify whether there is, in fact, widespread court activity under the Act and that the ADA does have remedial teeth.

We also believe that a number of ADA-related policy issues would benefit from research. For example, the ADA requires that both public and private organizations that offer examinations and courses necessary for the pursuit of higher education or professional and trade certification administer those tests under conditions that are accessible to persons with disabilities. We have received numerous complaints of discrimination in testing, and difficult issues have arisen particularly with regard to determining the amount of additional time that constitutes an appropriate test modification for persons with particular disabilities. Systematic research into this issue would assist us in ensuring the rights of individuals with disabilities while preserving the integrity of important standardized tests.

Another area where research would be beneficial is the issue of environmental illness. In drafting the final regulations for Titles II and

III, the Justice Department declined to make a categorical determination as to whether allergies and sensitivities to environmental chemicals qualify as disabilities under the ADA. Given the uncertainty surrounding the origins and effects of environmental illness, we instead adopted a case-by-case approach. Research that would help us assess the validity of claims for protection under the ADA would be helpful, as would information that would allow us to determine what modifications would be appropriate in particular cases.

We would also like to see systematic efforts to improve the professional training of architects and attorneys in ADA-related matters. Therefore, we would encourage research to support the development of ADA-related curricula for use in architecture and law schools to raise the ADA literacy level of these two professions.

Finally, we would urge continued research in the area of assistive technology. Technologies developed in the past few decades have allowed a great many individuals with disabilities to independently enter the mainstream of American life. There is still, however, a great deal of work to be done in this area that will allow the potential of the ADA to be fulfilled in practical ways.

For example, the ADA requires that places of public accommodation be accessible to persons with disabilities and that appropriate auxiliary aids and services be furnished to ensure equal enjoyment. Yet, for example, persons who are deaf are still largely unable to enjoy films shown in movie theaters, because effective technology that will allow closed captioning of films, as opposed to videotape, is not currently available. Research to develop appropriate technology for this setting would be most worthwhile.

Another area of technological research that would directly benefit persons with hearing impairments would be the development of telecommunication devices for deaf persons (TDDs) that would function in outdoor environments. Currently, because of the lack of effective technology, new banks of outdoor public phones, including those used in emergency call-box systems, are exempt from the requirements that apply to indoor pay phones regarding the installation of TDDs. For a person who is deaf, the absence of a TDD may create not only a minor inconvenience, but more significantly a major crisis in an emergency situation.

We also have a number of other ideas for research that do not fall into any of the categories mentioned thus far. For example, it would be worthwhile for research to systematically document the activities of individuals fraudulently holding themselves out as ADA experts. These individuals are playing on the fears of small businesses by exaggerating the requirements of the ADA and charging exorbitant fees for their advice and materials. Another possible research idea involves monitoring state and local government compliance with Title II. By January 26, 1993, state and local governments should have completed both transition plans and self-evaluations under ADA Title II regulation. We would suggest that a sample of these documents be reviewed and analyzed in order to give us a better idea of the steps being undertaken to comply with Title II.

These suggestions for research are only a few of the many areas from which we can directly benefit. In our zeal to breach new frontiers, however, we should be mindful of offering our continued support to valuable programs that are currently in place. Our vital technical assistance mechanisms should not be neglected. We should continue to allocate adequate funding towards these programs so that they may continue to provide high quality information and guidance to individuals with disabilities and entities with responsibilities under the ADA.

At this point I would like to recognize one of our partners in the technical assistance effort—the National Institute on Disability and Rehabilitation Research—and a cohost of this conference. We salute the efforts of our friends Bill Graves and Dave Esquith in establishing the ten Regional Technical Assistance Centers. NIDRR has given us full support in our governmentwide coordination of federal ADA technical assistance, and the Civil Rights Division is pledged to work closely with them as we meet future challenges.

Let me turn now to our enforcement efforts under the ADA and give you an update as to where we stand. Our enforcement philosophy is clear. We believe that the ADA is fair and balanced legislation. Attorney General Bill Barr and the Civil Rights Division are committed to enforcing the ADA vigorously, effectively, and fairly. Our compliance strategy is equally clear and is a simple one. It can be summarized in a phrase: "Educate and negotiate and litigate only when compliance is refused." What this means is that we are seeking to promote voluntary compliance with the ADA through an active outreach and public education effort. We will first seek to resolve complaints through a process of technical assistance and negotiation, and resort to litigation only when these avenues have proven unsuccessful.

In terms of our organization, on October 1 we established a new section in the Civil Rights Division, the Public Access Section, to handle many of our new responsibilities under the ADA. We have also assigned ADA responsibilities to two of our existing sections—the Coordination and Review Section and the Employment Litigation Section.

The Public Access Section, in its earlier guise as the Office on the Americans with Disabilities Act, was responsible for developing the Department's regulations under Titles II and III of the ADA which, we are very proud to say, were issued on time, a rather unusual phenomenon for Washington; thus allowing for the full 6-month adjustment period provided by the Act before the regulations went into effect.

The Public Access Section is also in charge of the Department's Technical Assistance Program, including the administration of grants and the coordination of ADA technical assistance activities governmentwide. Under our technical assistance program we have produced handbooks, manuals, and factsheets; handled thousands of calls to our information line at the rate of 3,000 a week; provided speakers for hundreds of conferences and seminars; and mailed out, literally, millions of documents. The Public Access Section also has responsibility for determining whether state and local building codes meet the requirements of the ADA and is currently reviewing a number of petitions for certification.

Since the January 26 effective date, we have steadily increased our staffing for our investigation and enforcement activities. The Public Access Section has assumed responsibility for the Department's litigation program under Titles II and III and is actively pursuing an ever-growing number of complaints.

When the Public Access Section receives a Title III complaint against a private entity, our first step is to send an acknowledgment to the complainant and notify the facility owner and/or operator. The investigation process is then begun in which the complainant is initially asked to provide more specific information about the respondent's facility and the alleged discrimination. Respondents are then requested to submit information relevant to the complaint.

On-site investigations are frequently necessary, especially when issues are raised involving alterations, new construction, or the removal of barriers in existing facilities. In many cases, a Public Access Section attorney will be accompanied by one of our staff architects who is able to make an expert assessment of the compliance problems and what it will take to solve them. We currently have a staff of ten attorneys and two architects involved in investigating complaints. We plan to add additional attorneys and architects during this fiscal year.

If, following this initial phase, the Public Access Section concludes that there is a violation of the ADA, we will first attempt to settle the matter voluntarily—through negotiation. We have found that frequently a problem situation can be resolved simply by bringing it to the attention of the owner-operator and by providing appropriate technical assistance. Because the ADA is so new, many covered entities simply do not know what the requirements are and how to apply them in their particular situation.

For me, the most satisfying experience comes from observing how successfully many businesses and governments have often voluntarily complied with and even gone beyond the ADA's requirements. I'm sure many of you have noticed new signs in retail shops offering to assist shoppers with disabilities and those in hotels directing customers with hearing impairments to the nearest TDD.

One of our attorneys, while providing technical assistance to a facilities manager in charge of over 60 shopping malls, happened to mention that a local mall in her town lacked van- accessible parking. Coincidentally, the mall was one of those owned by the manager's company and, soon thereafter, the company decided that it was "readily achievable" to provide two new, conveniently located van spaces. The same company has evaluated and improved the services it provides to customers with disabilities at all of its malls and has designed new brochures to highlight those services. That company obviously recognized the value of enhancing the services it provides to its patrons with disabilities.

We have also seen similar changes arising out of complaint investigations. For example, we helped to resolve a complaint against a private school for planning to hold graduation exercises in an inaccessible building. Our attorney explained the ADA's requirements for readily achievable barrier removal, surveyed the facility with school officials, identified the problems, and came up with practical solutions for resolving them, namely, installing a temporary ramp to the graduation hall, opening of an otherwise locked accessible restroom on an upper floor served by an elevator, and posting appropriate signage indicating the accessible route.

In another case we were able to work out, a privately operated art academy had refused to provide a sign language interpreter for a student who was to attend an intensive week-long seminar. Our attorney brought the ADA's auxiliary aids requirements to the school's attention and worked with the school and the complainant to determine exactly which sessions of the seminar involved complex verbal communication so as to require interpreting services. Once the school did that analysis, it realized that the cost of providing an interpreter would not be as high as it had feared, because an interpreter was not needed for large portions of studio sessions.

Of course, where a voluntary settlement cannot be obtained, the Public Access Section is authorized to litigate and we *will* litigate when the path of settlement is rejected.

When an action is brought by the Justice Department under Title III, the Department is entitled to seek a court order to stop discrimination. Injunctive relief might include a variety of remedies such as requiring a national athletic organization to modify its playing ability requirements for applicants for coach certification, a hotel to install a permanent ramp to its restaurant, a famous folk singer to provide a sign language interpreter at a concert, or a supermarket to restripe its parking lot to provide adequate accessible parking. These examples are from actual cases that, fortunately, we have been able to resolve short of litigation and are just a few illustrations of the type of injunctive relief we would seek.

The Department may also seek monetary damages for individual victims of discrimination. Monetary damages may not include punitive damages but may include compensatory damages. In addition, in certain cases where we deem it necessary to vindicate the public interest, we may seek civil penalties up to $50,000 for a first violation and up to $100,000 for any subsequent violation.

A different set of procedures applies when we receive complaints against state and local governments under Title II of the ADA. The ADA specifically provides that Title II is to be enforced in accordance with the procedures used to enforce Section 504 of the Rehabilitation Act of 1973. While Section 504 is enforced by each of over 25 federal agencies that provide federal grants, eight federal agencies, including Justice, have been specifically designated to handle the ADA Title II complaints. Each of the designated agencies was chosen because of its central role in enforcing Section 504. The Civil Rights Division's Coordination and Review Section handles the initial administrative investigation and adjudication of Title II complaints for which Justice is the designated agency. Where discrimination cannot be resolved through voluntary compliance, the case is referred to the Public Access Section for litigation.

Justice is authorized to handle complaints involving law enforcement, public safety, corrections, and courts. The more than 350 complaints we have received thus far focus on a broad range of issues, including TDD access to 911 emergency systems, physical access to municipal buildings, auxiliary aids in court proceedings, excessive force in arresting deaf persons, and treatment of prisoners with disabilities.

Our emphasis on negotiation and voluntary compliance has enabled us to achieve significant relief, even in the absence of formal findings of discrimination and litigation. For example, a 22-state bar association recently agreed to accommodate an individual with a learning disability by providing him with more time in which to complete the bar examination based on an individualized assessment of the individual's needs; a city consented to provide notices of meetings and agendas in formats that are readable by individuals with vision impairments; and a state prison system agreed to reassign an inmate with mental and physical disabilities caused by a traumatic head injury to a facility with appropriate medical care for his needs.

We have referred over 350 complaints involving other categories of state and local government activity to the appropriate federal agency responsible for that subject matter. For example, we have referred complaints involving access to school libraries and auditoriums to the Department of Education, barriers to public housing authority rental offices to the Department of Housing and Urban Development, lack of accessible hospital parking to the Department of Health and Human Services, and failure to provide curb cuts to the Department of Transportation.

In processing Title II complaints, the other seven designated agencies follow pretty much the same administrative procedures we use in investigating Title II complaints for which we are responsible. In other words, each agency investigates, issues formal letters of finding of discrimination, seeks voluntary compliance, and, if voluntary compliance cannot be achieved, refers the case to our Public Access Section for litigation.

The remedies available in Title II cases are exactly the same as those provided by Section 504 of the Rehabilitation Act. Until recently, only some federal circuit courts had granted compensatory damages, in addition to injunctive relief, under Section 504. The Supreme Court, however, recently held in *Franklin v. Gwinnett County Public Schools* that compensatory damages could be awarded under Title IX of the Education Amendments of 1972, which bars sex discrimination in education programs receiving federal financial assistance. We believe that since Section 504 was modeled on Title IX, it is likely that all circuits will follow the holding in *Franklin* and will view compensatory damages as an appropriate Section 504 remedy, and therefore, available under Title II.

Let me note one other aspect of our enforcement program that should be of particular interest. Under Title I of the ADA, the employment provisions which are generally enforced by the Equal Employment Opportunity Commission (EEOC), the Attorney General has litigation authority with respect to complaints against units of state and local government. When EEOC investigates a charge against a public entity, makes a reasonable cause finding, and fails in its efforts to conciliate, it will then refer the charge to the Employment Litigation Section of the Civil Rights Division. That section may then litigate the charge or, in the alternative, issue a Right to Sue letter to the complainant. The Employment Litigation Section also exercises the Division's independent Title I authority to sue 25 units of state and local government that we believe are engaged in a pattern or practice of employment discrimination.

Of course, since the enactment of the Civil Rights Act of 1991, the remedies available under Title I have expanded from injunctive relief and back pay to include compensatory damages that are subject to a floating cap, depending on the number of employees. While punitive damages are available in cases against private employers under the 1991 Act, they are not available in claims against government agencies.

One additional note on employment: We are working closely with the EEOC to develop a coordination regulation for handling employment complaints for which there is overlapping coverage under Section 504 or Title II, and Title I of the ADA. For example, a municipal police department that receives federal funds for a crime control program would be covered three ways: by Title II of the ADA as a "public entity," by Section 504 as a recipient of federal financial assistance, and by Title I of the ADA as an employer with 25 or more employees. A final rule laying out the ground rules for federal agency handling of employment complaints with overlapping coverage will be published in the near future.

The final piece on carrying out our philosophy of "first educate and negotiate" is an effective program of technical assistance. Providing high-quality technical assistance is critical if we are to achieve our goals while keeping costly litigation at a minimum. We have provided over $3.4 million in grant monies to 19 business and disability advocacy groups to fund projects designed to promote voluntary compliance with the ADA. One of our top priorities has been to encourage projects of national scope that will enable business, government, and individuals with disabilities to work as partners in promoting compliance. We were particularly pleased that, in this year of very tight budgets, the Congress, with the strong support of Senators Kennedy, Dole, and Harkin, has provided an additional $2,500,000 in the FY 1993 budget to fund additional technical assistance projects.

Fifteen months after their issuance, our ADA regulations are well on their way toward becoming part of the fabric of American life. It is gratifying to see the language of the ADA and our regulations become part of the common vocabulary of ever-widening circles of Americans. Ideas that seemed novel, or even threatening, to many people nearly a year ago are now commonplace for growing numbers of decision makers in our public and private institutions.

As I mentioned at the outset, we believe that our ADA regulations maintain the law's careful balance between protecting the right of individuals with disabilities to equal access to the mainstream of American life and recognizing the legitimate needs of government and business for efficiency and profitability. Through the incorporation of limiting concepts such as "readily achievable," "undue burden," "reasonable accommodation," and "undue hardship," which take into consideration the economic health of individual businesses and government units, the ADA protects essential rights and, at the same time, promotes economic growth.

In the relatively brief period we have been working with this revolutionary statute, there is one clear conclusion: The ADA is not a "zero sum game" where one group's gain comes only at the expense of another's loss. Every sector of society will benefit from the ADA's swift and effective implementation. Already, there is a growing appreciation, particularly in the private sector, not only that it is relatively easy to live with the ADA's requirements, but that business opportunities—and profits—can be increased by opening the marketplace to individuals with disabilities, a large and previously underserved group of American consumers. And in this period of fierce international economic competition, we can no longer fail to fully tap the employable skills and dedication of millions of Americans with disabilities.

Perhaps the most important question in the ADA debate is one that often receives the wrong answer: Just who are the beneficiaries of this law? It is not simply those who use wheelchairs or who are blind, deaf, or hard of hearing. The ADA protects individuals with a wide spectrum of disabilities. But they are not the only beneficiaries of the Act. All businesses that will now be able to employ people with disabilities or sell their products or services to them benefit by the ADA. And there are more: Family members and friends of those with disabilities gain by a law that brings greater fulfillment and independence to loved ones.

And finally, the beneficiaries include all of us—not only because it means we will live in a better, more compassionate community. We will benefit by the ADA because someday, every person in this room may need its protection and its guarantees. As I have learned from my friends in the disability community, the world is divided into two groups—those with disabilities and those who are **temporarily** able. As a result of an accident, a disease, or simply the passage of time, anyone may awake one day and realize that the ADA now has special meaning to one more individual.

For that reason, if for no other, I urge you to help spread the message: The ADA is a good law, an essential law, and we must all work hard to see it is implemented so that its promise becomes a reality for the entire nation. Thank you.

Session II (Part 1)

Putting Research to Work for the Realization of the Goals of the ADA: The Perspective of the Community of Persons with Disabilities

Moderator: **A. Kent Waldrep, Jr.,** National Council on Disability

Speakers: **Simi Litvak,** The World Institute on Disability

Andrew Batavia, Abt Associates

Discussant: **Harlan Hahn,** University of Southern California

Mrs. Parrino turned the session over to moderator A. Kent Waldrep, Jr., Vice Chairperson of NCD. Mr. Waldrep introduced Dr. Simi Litvak of The World Institute on Disability.

Summary of Dr. Litvak's Paper

Dr. Litvak's paper, "Putting Research to Work for the Realization of the Goals of the ADA: Perspectives of the Disability Community," focused on the ambivalence felt by many in the disability community about disability-related research. Dr. Litvak examined the reservations the disability community has about research and highlighted the use of research in past disability policy development. She discussed the concerns of the disability community about the direction that research on the ADA should take in its policy implementation stage. She then focused on suggestions for ADA-related research that would be very useful during the implementation period. She concluded with a description of outstanding research agenda items regarding policy and underserved groups.

Dr. Litvak's Presentation

In presenting her paper, Dr. Litvak summarized the main points, concentrating on the need for disability researchers to ask questions that are relevant to the lives of people with disabilities and to the needs of policy makers. She characterized disability policy researchers as having three main tasks: background research to determine needs, support and direction during policy implementation, and outcome evaluation. She stated that it is too early to evaluate the merits of the ADA at the present time; evaluators should concentrate on how the law is being implemented. She listed a number of areas, such as outdated access guidelines, that cause difficulties for those seeking to implement as well as enforce the law.

In terms of future research, Dr. Litvak urged that the numerous individuals, groups, and interested agencies of the federal government work together to fund and generate research that cuts across disciplines. She listed a number of areas—ranging from definition of concepts such as "equality," to better documentation of the needs of underserved populations, to defining the needs of disabled individuals who do not take advantage of the ADA—that need further attention from researchers.

Mr. Waldrep then introduced Mr. Andrew Batavia of Abt Associates.

Summary of Mr. Batavia's Paper

Mr. Batavia's paper, *The Failure of Disability Policy Research: Sources and Solutions,* was premised on the notion that disability policy research has failed to meet the needs of advocates and policy makers for empirically based knowledge to advance the disability policy agenda. It stated that while researchers had been effective in identifying problems, they had been less effective in analyzing solutions, and that disability policy research had been hampered in its efforts by issues of relevance, objectivity, competence, and adequacy of resources.

In the paper, Mr. Batavia called for a vitalization of disability policy research, both internally and externally. From within the field, the paper stated that researchers must ensure the relevance of their research by incorporating more meaningful and appropriate participation of people with disabilities into the research process. Mr. Batavia stated that researchers must ensure the objectivity of their research by not confusing the roles and objectives of the researcher with those of the advocate. From the outside, with few economic resources available, policy makers must be convinced that the field is worthy of investment; policy researchers must be persuaded that the field is worthy of their efforts.

Mr. Batavia's Presentation

In discussing his paper, Mr. Batavia reiterated the main points, focusing on specific examples where the relevance, objectivity, competence, and adequacy of resources for disability policy research have reduced the overall research effort to "a dismal failure." He stated that the field has not served the needs of disability policy and has failed to advance people with disabilities to the next stage of the independent living movement. Specifically, with regard to the ADA, Mr. Batavia noted that disability researchers could not answer the questions of lawmakers. However, the ADA passed even without documentation of need. No baseline data exist to assess the implementation of the ADA.

In terms of solutions, Mr. Batavia stressed the need to involve more persons with disabilities in the disability policy process as researchers and peer reviewers. Separation of the roles of researchers, advocates, and policy makers will benefit all. He called on the appropriate public and private institutions to invest in both policy and research and to support the publication of research conducted under their auspices.

Mr. Waldrep called for questions and comments from the audience.

Discussion

Conference participants began a spirited discussion of Mr. Batavia's statement that advocacy conflicts with policy research. A point was made that advocacy groups support much of the research involving disability policy. Thus, no research is value-free. Several suggestions for improving the quality of disability policy research were made:
(a) advocate after conducting research, not before; (b) train more researchers with disabilities; (c) take steps to bring disability policy research into the mainstream scientific literature, which will necessarily dictate the caliber of disability policy research; and (d) establish objectivity by truthfully describing research methods and assumptions and by separating findings from recommendations.

Individual Breakout Sessions

Individual breakout sessions on *Equality of Opportunity, Full Participation, Independent Living,* and *Economic Self-Sufficiency* followed Session I. The results of these sessions are found in Section II: *Conclusions and Recommendations, Breakout Sessions.*

Session II (Part 2)

Putting Research to Work for the Realization of the Goals of the ADA: The Perspective of Minorities and Other Underserved Populations

Moderator: **Frederick Bedell,** National Council on Disability

Speakers: **Paul Leung,** University of Illinois at Urbana-Champaign

Sylvia Walker, Howard University

Discussant: **Evelyn Davis,** Harlem Hospital

Dr. Fred Bedell, Acting Executive Director of NCD, moderated the session. Dr. Bedell noted that NCD had recently cosponsored a conference with Jackson State University, an Historically Black College in Jackson, Miss., entitled *Meeting the Unique Needs of Minorities with Disabilities: Setting an Agenda for the Future.*

Dr. Paul Leung of the University of Illinois at Urbana-Champaign then discussed *Putting Research to Work for the Realization of the Goals of the ADA: The Perspective of Minorities and Other Underserved Populations,* a paper that he coauthored with Dr. Sylvia Walker.

Summary of Dr. Leung's Paper

In his portion of the paper, Dr. Leung argued that racial/ethnic persons with disabilities have often been ignored in disability policy research and that little has been done to promote their inclusion. At the same time, racial/ethnic minority populations have grown the most during the past decade in the United States. He argued that there is an appalling lack of data related to racial/ethnic populations with disabilities; data that are available were often in a form not usable or not effective for the formulation of policy. In addition, he stated that some of the basic assumptions of the ADA may be at odds with the cultural value systems of racial/ethnic minority populations. Increased emphasis on disability policy research that targets racial/ethnic minority populations with disabilities is necessary.

Dr. Leung's Presentation

In his presentation, Dr. Leung pointed out that the disability community has traditionally been led by middle- and upper-income whites. However, factors such as poverty and minority status make disability worse. Lack of data certainly does not indicate lack of need. To effectively measure need in racial/ethnic minority communities, methods of data collection may need to change to bring in new perspectives and to break down the distrust between racial/ethnic minority communities and researchers. Researchers also need to pay more attention to the differences among minority subgroups and the lack of data for these smaller communities. Dr. Leung pointed out that racial/ethnic minority communities often fail to demand attention and services because the mind-set of the individual calling attention to a problem is a Western one.

Dr. Sylvia Walker of Howard University spoke next on her paper.

Summary of Dr. Walker's Paper

Dr. Walker's portion of the paper, coauthored with Dr. Leung, concerned the growing incidence of disability in racial/ethnic minority populations, a growth that occurs in direct proportion to increasing poverty among pregnant women. The increasing effects of pediatric Acquired Immunodeficiency Syndrome (AIDS), AIDS in adult populations, and an increase in maternal substance abuse, particularly crack cocaine, have raised new challenges for researchers in the field of disability policy. Data cited from hospitals serving large urban minority populations with severe drug use problems indicated that the percentage of substance-exposed new births is as high as 40 percent of live births. The long-term effects of maternal substance abuse on the development of young children are unknown.

Dr. Walker's Presentation

In her presentation, Dr. Walker indicated that minorities with disabilities earn less and are more likely to be unemployed than their majority counterparts. Ethnic groups are also not homogeneous; some groups are overrepresented in disability categories. Further complicating matters, some service providers and small business owners in poor minority communities have difficulties meeting the needs of persons with disabilities. Minority persons with disabilities are not on a level playing field with their majority counterparts. The ADA has promise and benefits for the entire society, but they are not being fully realized in minority racial/ethnic communities.

Discussant's Comments

Dr. Evelyn Davis of Harlem Hospital discussed her experiences serving the minority community in New York City. She pointed out that the developmental difficulties (mild mental retardation, autism, etc.) of children born with drug exposure, HIV, and alcohol exposure are unexpected disabilities for which service providers and educators are unequipped. These children and their parents are not generally individuals who ask for services under the ADA. Thus, the disability community must insist on further research in these areas and train researchers to cope with the special needs of these populations.

Discussion

Panelists and members of the audience discussed the lack of federal funds to assess disability issues affecting minority communities. Dr. Walker noted that data concerning minorities in general are not applicable to minorities with disabilities. Dr. Davis reported that she and several colleagues in New York have set up a research consortium to develop a clearinghouse for data specific to minorities. She stressed the importance of training researchers to elicit data using culturally appropriate techniques.

Reports From Breakout Sessions

Moderator: **John A. Gannon,** National Council on Disability

Sessions:

- Equality of Opportunity—**Andrew Batavia,** Facilitator
- Full Participation—**Simi Litvak,** Facilitator
- Independent Living—**David Pfeiffer,** Facilitator
- Economic Self-Sufficiency—**Paul Leung,** Facilitator

A. Equality of Opportunity

Mr. Andrew Batavia presented a series of transparencies detailing the discussion of the Equality of Opportunity Breakout Session. The group's discussion fell into six categories: general issues, employment, education, public accommodations, government services, and telecommunications.

The group defined a number of general issues that extend across the specific areas of employment, education, public accommodations, government services, and telecommunications. These general issues that affect equality of opportunity include access to health care; access to personal assistance services; monitoring of compliance with the ADA; defining and achieving equality of opportunity; increasing public awareness of the ADA and the right to equality of opportunity under the ADA; and the need for basic data on equality of opportunity in employment, education, etc.

For each of the five remaining categories, the group prioritized two issues for future research.

Employment

1. How have employers responded to the ADA? Have they determined their responsibilities under the ADA? How? How have they responded to those new responsibilities?
2. Identify work disincentives associated with Supplemental Security Income (SSI), Social Security Disability Insurance (SSDI), and the lack of adequate health insurance for people with disabilities.

Education

1. What are the best models of special education and integration of students with disabilities into mainstream classes?
2. What programs and models work best for the transition from school to work?

Public accommodation

1. Identification of unmet needs.
2. Determination of the effectiveness of accommodations such as architectural modifications.

Government services

1. How do differing definitions of disability in federal programs interact with one another to affect equality of opportunity for government services?
2. How can interpretations of the ADA be coordinated across states?

Telecommunications

1. How do public carriers train personnel to meet standards of effective service?
2. How should systems designers be trained to consider accessibility factors?

B. Full Participation

Dr. Simi Litvak presented transparencies showing highlights from the *Full Participation* breakout session.

The group felt that any research conducted on full participation must consider a number of issues:

1. Determine the quality and degree of participation.
2. Institute freedom of choice in considering participation status.
3. Are separate but equal arrangements truly equal and do they allow full participation?
4. Barriers to participation are multiple—the ADA is only a guideline, not a guarantee to full participation.
5. Barriers to full participation arise if an individual does not know what opportunities are available to him or her.
6. The dissemination of information about the ADA is incomplete, meaning that barriers to full participation remain intact for individuals who are not familiar with the ADA.
7. Who makes up the reference group by which full participation is judged? How can participation be evaluated across the spectrum of disability?
8. The current national debate over health care obviously affects people with disabilities, and immediate research is needed on the effects of the different proposals on people with disabilities, particularly proposals for prevention of disabilities.
9. People with disabilities are not isolated from society but are a part of the whole, meaning that full participation should be considered from both individual and societal perspectives.
10. All of the goals of the ADA are extremely complex and require input from people with disabilities, philosophers, and people who study ethical issues using quantitative, qualitative, and participatory research methodologies.

C. Independent Living

Dr. David Pfeiffer of Suffolk University, discussed the findings of the *Independent Living* breakout session.

Dr. Pfeiffer reported that the group had based its discussions on the morning conference session. Group members agreed that the disability community and disability researchers are moving from a medical paradigm to a disability paradigm. This movement presents an obvious question: How is research based on this new paradigm translated into policy?

Although group members were not able to answer this overarching question, they discussed the advantages and disadvantages of quantitative and qualitative methodologies. The group developed two research priorities with respect to independent living:

1. Operationalize what "independent living" means and test its implications.
2. Study the implementation of the ADA now and its outcomes later.

D. Economic Self-Sufficiency

Dr. Paul Leung reported on the *Economic Self-Sufficiency* breakout session.

The group defined economic self-sufficiency as follows:

> *An individual is economically self-sufficient if that individual earns or can earn enough to meet his or her basic life needs. A household is economically self-sufficient if someone in that household (or the household collectively) earns enough to meet the household's basic needs.*

The group then established a number of research priorities in the general area of economic self-sufficiency:

1. Establish the need for baseline national statistics on economic self-sufficiency for people with disabilities.
2. Identify federal agencies that will support such a survey.
3. For people with disabilities who meet the various federal eligibility criteria (such as those for SSI and SSDI), what are the factors that separate those who work from those who do not work?
4. Examine upward mobility within jobs for persons with disabilities.
5. Examine the quality of training provided to persons with disabilities; determine what works in promoting economic self-sufficiency.
6. Compare lifetime earnings and upward mobility for people with various disabilities with those of the general population.
7. Establish the need for a variety of integrated programs.
8. Establish the need for more stringent evaluations of programs intended to promote economic self-sufficiency among people with disabilities; define the success for such programs.
9. Determine what answers are needed by policy makers.
10. Extend research to examine economic self-sufficiency issues beyond the working age of persons with disabilities.
11. Document those programs and policies that are effective.
12. Explore ways to better utilize existing data.

Discussion

The fourth group was urged to add a recommendation to document the importance of reasonable accommodation in the workplace in enhancing the economic self-sufficiency of workers.

The discussion then turned to the difference between primary and secondary disabilities. Several members of the audience discussed the ethical implications of genetic testing and prenatal screening for disabilities. Abortion, suicide, and assisted death as ethical and civil rights issues were also debated. Mrs. Parrino stated the position of NCD that abortion should not be a form of prevention of disability.

Tuesday, December 8, 1992 **Plenary Session**

Session III

Shaping an Interdisciplinary Field of Disability Studies Responsive to the Goals of the ADA

Moderator: **David Gray,** National Center for Medical Rehabilitation Research

Speakers:
- Economics—**David Dean,** University of Richmond
- Engineering—**Andrew Schoenberg,** University of Utah
- Health—**Gerben DeJong,** National Rehabilitation Hospital
- Social Policy—**Irving K. Zola,** Brandeis University
- Vocational Rehabilitation—**Susanne M. Bruyère,** Cornell University

Discussant: **Mary Chamie,** United Nations

Dr. Gray thanked NCD for sponsoring the conference. He indicated that future federal requests for applications and requests for proposals grow out of this type of conference. He commented that the disability field needs to collapse across "etiologies" and focus on "function."

Economics

Dr. David Dean, University of Richmond

Dr. Dean began by noting that the business community has railed against the costs of implementing the ADA. However, the costs of reasonable accommodation may not be that high. He challenged researchers to determine the costs of reasonable accommodation and assistive technology to firms, using terms as specific as possible. Case studies at the company level can help determine the costs of compliance with the ADA. Controlled experimentation to determine discriminatory hiring practices can be used to encourage businesses into complying with the ADA. In general, however, owners may be more likely to comply with the ADA if they are convinced that it is in the best interests of their business to do so. One way to do that is to measure reduced costs traceable to compliance with the ADA in areas such as lower workers' compensation expenditures and reduced long-term disability benefits. Businesses must also be informed of the costs of noncompliance with the ADA. Finally, researchers should look at the costs versus benefits of return-to-work programs, the estimates of which have been wildly inflated by businesses.

Engineering

Dr. Andrew A. Schoenberg, University of Utah

Rehabilitation engineering is the application of engineering principles and technical expertise in the provision of assistive technology to help a person with a disability achieve his or her functional goals. There are approximately 500 rehabilitation engineers in the United States. However, Dr. Schoenberg's experience in Utah has revealed that the mechanisms that support the purchase, servicing, and delivery of assistive technologies are very weak. The engineering profession must reeducate itself in light of the ADA.

Reimbursement for rehabilitation engineering services are not readily approved by third-party payers, Medicare, or Medicaid. The traditional system of "medical necessity," prescription of devices by a physician, and delivery of such devices by durable medical equipment suppliers is still the predominant paradigm. Significant changes in this paradigm will need to be designed if assistive technology is to be delivered effectively to reduce barriers for employment and integration of persons with disabilities into the larger community.

The engineering professions, including rehabilitation engineering, will need to increase their awareness, role, and understanding of the provisions of the ADA and how engineering can enhance the lives of people with disabilities.

Dr. Schoenberg also spoke briefly about the employment status of persons with disabilities and the impact of the ADA on that status. He noted that 75 percent of people with spinal cord injuries are unemployed. Among the reasons for this high unemployment rate are health factors, lack of education, and lack of job skills. Barriers to work and improved living standards include lack of assistive technology, and rehabilitation engineers can have the most immediate impact in this area. Policy barriers to improved employment of people with disabilities include the high cost of health insurance (if provided at all) for prospective employees. Additionally, the attitudes of employers toward individuals with spinal cord injuries are often negative.

Health

Dr. Gerben DeJong, National Rehabilitation Hospital Research Center

Dr. DeJong noted that the disability community's historical aversion to the medical model has meant that, until recently, the community has not viewed health care as an important policy area. Within health care, each health discipline views people with disabilities differently and seeks to achieve somewhat different outcomes. However, health care issues ranging from insurance to overall systemic reform have direct implications for people with disabilities and are affected by the ADA.

Dr. DeJong's outline listed a number of concrete steps that could be taken to develop such a research capacity. Dr. DeJong stressed that resources and leadership are needed from a whole range of public and private groups, including the federal government, the academic community, and the disability community.

Social Policy

Dr. Irving K. Zola, Brandeis University

Dr. Zola discussed the evolution of disability studies within the discipline of sociology. For many years, the dominant theoretical model for disability was a biomedical model that focused on acute illness. During the 1970s and 1980s, the field of disability studies gradually evolved into its own discipline, formed by the work of activists in a number of fields, including the independent living movement and feminism. In the 1990s, disability studies are again undergoing transformation. Should they be combined as a field? If so, how? This discussion is analogous to the debate on forming a separate women's health discipline. People who are involved in disability studies continue to debate the issue.

Vocational Rehabilitation

Dr. Susanne Bruyère, Cornell University

Dr. Bruyère reviewed the current relationship between vocational rehabilitation and disability policy research, including existing vocational rehabilitation service delivery and personnel categories, personnel education and training structures, and social policy interests with respect to vocational rehabilitation. She then discussed the implications of the ADA for vocational rehabilitation service delivery, personnel structure, personnel education and training, and research. In general, the ADA has facilitated greater attention to and augmentation of these fields.

Dr. Bruyère pointed out that professionals in the field of vocational rehabilitation have traditionally seen themselves as helpers or experts in the delivery of services; that perspective needs to shift to the empowerment model. Better interfaces are needed between the vocational rehabilitation community and other groups, such as medical professionals, businesses, researchers, and the community at large. Interdisciplinary interfaces are needed in areas such as economics, engineering, health, and social policy. Dr. Bruyère enumerated a number of steps to develop disability research in vocational rehabilitation and discussed the resources needed to support these steps.

Discussant's Comments

Dr. Mary Chamie, United Nations, proposed two rules for interdisciplinary research: (a) establish full exchange across the disciplines, and (b) include measures that ensure that the research is fully interdisciplinary, such as internships that allow individuals from one discipline to share the activities of another. With regard to controlled experimentation in the disability field, Dr. Chamie suggested that researchers should also consider controlling the environment (width of doors, height of steps, etc.) in any experiment, not just the participants.

Discussion

In discussing the presentations, members of the audience debated the need for one or more interdisciplinary disability policy research institutes. Participants indicated that, without an entity that can provide quick turnaround on research, all people with disabilities will not be able to effectively lobby policy makers. Several individuals argued that there should not be one single voice speaking for all people with disabilities. The centralization of research funding, rather than centralization of research, was also suggested.

Several members of the audience submitted suggestions for additional research. One example of these was in the field of life insurance, specifically, the costs of and barriers to acquiring life insurance for persons with disabilities.

Session IV

Strategies for Adopting Common Nomenclature That Is Responsive to the Goals of the ADA: National and International Experiences

Moderator: **Gerry Hendershot,** National Center for Health Statistics

Speaker: **Michel Thuriaux,** World Health Organization

William Frey, Disability Research Systems, Inc.

Discussants: **Adele Furrie,** Post Censal Surveys Statistics, Canada

Donald Patrick, University of Washington

Dr. Gerry E. Hendershot, National Center for Health Statistics

Dr. Hendershot spoke briefly about the importance of terminology and the need to reach consensus on terms that are central to advancing disability research. He then introduced Dr. Michel Thuriaux, Division of Epidemiological Surveillance and Health Situation and Trend Assessment, World Health Organization (WHO); Dr. William D. Frey, President, Disability Research Systems, Inc.; Adele Furrie, Statistics Canada; and Dr. Donald L. Patrick, University of Washington.

Summary of Dr. Thuriaux's Paper

Dr. Thuriaux's paper, *Relevance of an International Classification System for the Realization of the Goals of the ADA*, concerned the International Classification of Impairments, Disabilities, and Handicaps (ICIDH) currently being used by WHO for disability-related research. In the paper, Dr. Thuriaux argued that an international classification system can help identify the conditions and circumstances that may foster discrimination against people with disabilities, both at the individual level and at the level of the interaction between the individual and society. Additionally, such a classification system demonstrates the interaction of individual characteristics with constraints linked to the societal and physical environment in the development of the "handicapping" process. Careful use of an agreed-upon nomenclature will help the international community better address the increasing issues of disability. Dr. Thuriaux's paper also illustrates ways in which ICIDH addresses the various goals of the ADA. Dr. Thuriaux discusses the limitations of ICIDH, as well as current proposals for its revision.

Dr. Thuriaux's Presentation

In his presentation, Dr. Thuriaux reiterated the main points of his paper. He stressed that the structure of the "handicap" classification is radically different from all other ICIDH-related classifications. The items are not classified according to individuals or their attributes but rather according to the circumstances in which persons with disabilities are likely to find themselves, circumstances that can be expected to place such individuals at a disadvantage.

Dr. Thuriaux asked the audience to consider what might be an appropriate English-language umbrella term to cover the overall spectrum of experiences associated with impairment, disability, and handicap.

Summary of Dr. Frey's Paper

Dr. Frey's paper, *Nomenclature Which Is Specific to the Goals of the Americans with Disabilities Act*, further clarified the relevance of the concept "handicap" to the ADA. Dr. Frey then turned to his experiences in applying the concept of "handicap" to the design of expected outcomes of education for students with disabilities. The paper briefly describes the disablement process as proposed by WHO; discussed problems in the organization of special education and rehabilitation services arising from a preoccupation with physical and mental impairments in the individual; described the application of the ICIDH framework to the development of expected educational outcomes for students with disabilities; and discussed a number of the issues that are important for the development of policy associated with the ADA and related legislation.

Dr. Frey's Presentation

In his presentation, Dr. Frey stressed the importance of the term "handicap," which is used within ICIDH to describe the experience faced by people with injuries, disorders, or diseases. He argued that the ICIDH usage of "handicap" supports the goals and intent of the ADA. Dr. Frey insisted that agreement on terminology and on a model of disablement will lead to better data collection, which will in turn affect the adoption of policies concerning persons with disabilities. Despite its faults, the ICIDH can provide such a unifying terminology and model for disability researchers, one that is in tune with the goals of the ADA.

Dr. Frey also touched upon his experiences using a model based on the ICIDH to evaluate special education services in Michigan schools. Dr. Frey's model includes definitions of desired adult living roles and generic outcomes for students with disabilities. The emphasis of the model is on process rather than outcomes.

Discussants' Comments

Ms. Adele Furrie, of Post Censal Surveys, Statistics Canada, began her comments by insisting that using a common nomenclature directed toward a common goal is essential to making the various pieces of research fit together, particularly in times of fiscal restraint. Ms. Furrie highlighted examples in the papers of Drs. Thuriaux and Frey that show the viability of ICIDH in conducting such research.

Ms. Furrie then discussed her experiences with Post Censal Surveys, Statistics Canada in developing a comprehensive database to quantify the barriers faced daily by persons with disabilities. ICIDH was chosen as the framework for three major national surveys in which its concepts were operationalized and made relevant to members of the public. For two groups in particular—children and persons with disabilities in the area of mental health—the ICIDH model proved insufficient. Statistics Canada turned to advocacy groups for assistance in these two areas, assistance that extended into advocacy for funding the second and third stages of the research.

Canada's comprehensive national strategy for persons with disabilities encompasses areas addressed by the ADA. All research activities funded by the Canadian government use the ICIDH definition of disability. The Canadian experience validates the use of ICIDH, with operational modifications, as a model for policy research.

Dr. Hendershot commented that there has been no U.S. survey on disability since 1981.

Dr. Donald Patrick agreed with the other panelists that the choice of common research terms is important. However, ICIDH is only one way to look at the experiences of people with disabilities. ICIDH must be put within the context of prevention strategies that work at more than the disablement process in areas such as environmental interventions; that adopt a complete life course expectancy from infancy to older adulthood; that include developmental disabilities, injury-related disabilities, and chronic conditions; and that focus on the improvement of quality of life as defined by society at large and by persons with disabilities in particular.

With regard to the ADA, Dr. Patrick contended that discrimination is only one source of disadvantage; questions of equity and equality are at the root of disability policy research. A strong need exists for local, area-based studies like those sponsored by the National Institute for Mental Health in the field of mental health.

Discussion

Members of the audience discussed the need to agree on terms and the challenges involved in reaching agreement. It was suggested that persons with disabilities should be asked to define nomenclature describing their disabilities (if indeed broad categories *should* be defined). It was suggested that disability is a process that should be given an umbrella term such as "disablement." On the other hand, it was argued that "disablement" may be too broad a term for researchers to use in a meaningful way; being disabled involves a number of differing planes of experience that should not be confined under one term.

With regard to the overlap between the categories of ICIDH and the goals of the ADA, it was suggested that "handicap," as used in ICIDH, is insufficient to represent the goals of the ADA; the role of the social environment in contributing to disadvantage was reiterated, as was the need to include quality of life concerns. The pejorative connotations of "handicap" in American usage were mentioned.

Individual Breakout Sessions

Individual breakout sessions on *Issues Related to Special Populations, Emerging Issues, Building a Disability Study Discipline,* and *Creating a Common Nomenclature and Classification* were conducted. Please consult Section II: *Conclusions and Recommendations, Breakout Sessions.*

Session V (Part I)

Research Strategies for Statistics: Survey Data and Quantitative Research

Moderator: **Scott Campbell Brown,** Department of Education

Speakers: **Lois M. Verbrugge,** University of Michigan

Michelle Adler, Department of Health and Human Services

Discussants: **Mary Chamie,** United Nations

Michael Adams, Centers for Disease Control

Dr. Scott Campbell Brown, U.S. Department of Education, introduced Dr. Lois Verbrugge, University of Michigan, and Ms. Michelle Adler, U.S. Department of Health and Human Services.

Summary of Dr. Verbrugge's Paper

Dr. Verbrugge's paper, *Survey Research on Disability: Its Relevance for the ADA,* gave an overview of disability and stressed the diversity of the disability experience. The paper covered five broad topics: a perspective on disability that utilizes good research; key information that researchers should have about disability in the U.S. population; how effectively surveys can report the progress of the ADA; essential developments in data management for better disability statistics; and the federal government's role in production of disability statistics and generation of scientific research. The paper closed with five specific recommendations for quantitative researchers.

Dr. Verbrugge's Presentation

Dr. Verbrugge's presentation echoed the main points of her paper. She characterized disability as a type of relationship between a person and his or her environment. Disability occurs when a gap opens between personal capability and an activity's physical and mental demands. Disability can be alleviated either by increasing capability or reducing demand.

Dr. Verbrugge's five recommendations for researchers included calling for clarity (although not necessarily uniformity) in scientific terminology; illuminating the disablement process, across all ages and conditions, so as to learn about interventions that work; recognizing that population surveys cannot directly reveal the ADA's success but can help track the course and nature of disability in the population; and measuring the disability experience on its own terms and at its own pace, using appropriate language and receiving input from the community of persons with disabilities. Dr. Verbrugge urged that the federal government take principal responsibility for generating large-scale disability surveys and for providing funds for analysis.

Summary of Ms. Adler's Paper

Ms. Adler's paper, *Federal Disability Data: Creating a Structure in the 1990s to Further the Goals of the ADA,* placed the ADA in the context of other landmark pieces of civil rights legislation in the 20th century. While legislation such as the Social Security Act of 1935 can be evaluated according to a statistical structure to measure its progress and effects, no similar statistical structure exists to describe the role of disability in American society. The paper examined how federal disability data in the 1990s can be structured to be useful in policy debates that will further the goals of the ADA.

Ms. Adler's Presentation

In her remarks, Ms. Adler argued that a broad array of data are needed to evaluate the various federal programs serving the needs of persons with disabilities—almost 40 million Americans. None of the existing major federal surveys are specifically targeted toward understanding or documenting disability. Among the options available to provide data about disability are the Year 2000 Decennial Census, the Survey of Income and Program Participation, the Current Population Survey, and the National Health Interview Survey (NHIS). The 1994/95 Disability Survey, a supplement to NHIS, is the most ambitious and most promising source of disability data, although it has not yet been completely funded, nor will it begin until January 1994.

Discussants' Comments

Dr. Brown then introduced Drs. Michael Adams, Centers for Disease Control, and Mary Chamie, United Nations, who discussed the two presentations.

Dr. Adams divided conference presentations into two broad categories: research regarding the goals of the ADA (represented by Dr. Verbrugge), and a national scorecard on the outcomes of the ADA (represented by Ms. Adler). Dr. Adams confined his remarks to the ADA scorecard.

With regard to the scorecard, Dr. Adams urged that evaluators not wait until the "ideal" evaluation is designed. Researchers must use the best available measures to begin evaluating progress toward the four major goals of the ADA. Although the data sets mentioned by Ms. Adler are not ideal, they can help researchers determine the status of the community of persons with disabilities in light of the ADA and uncover possible shortcomings. In this regard, securing funds for the 1993/94 Disability Survey is particularly important. It would also make sense for the United States to plug into the momentum already achieved by the ICIDH in Europe.

Dr. Chamie noted that the common goal of standards for disability data collection challenges countries and/or organizations to clearly state their objectives and to acknowledge the underlying policies that drive their disability statistics programs. Few international guidelines or recommendations exist in this area. Current international analysis of socioeconomic characteristics of persons with disabilities indicates that even though the way in which countries measure educational attainment—or economic activity or marital status—is quite similar, the educational and occupational data on persons with disabilities cannot always be readily compared due to strong differences in the way people with disabilities have been defined across programs of education, social welfare, and health. She noted that such findings underscore the necessity of international guidelines and survey standards of data collection on disability so that rates may be more comparable and more meaningful, both within and across countries.

A major international event affecting survey and program planning has been the United Nations World Programme of Action Concerning Disabled Persons (WPA) adopted by the United Nations General Assembly at its 37th session in 1982 (Resolution 37/52). The purpose of the WPA is to promote effective measures for prevention of disability, rehabilitation and realization of the goals of full participation of persons with disabilities in social life, and development of equality. The major areas of action addressing these goals were viewed as prevention, rehabilitation, and equal opportunity. At the same time that the WPA was being formulated by the United Nations, the World Health Organization was preparing the trial ICIDH (WHO 1981). The broad concepts of the ICIDH were recognized by the drafters of the WPA and were included in its goals for improvement in the concepts and language for describing people who have impairments, disabilities, or handicaps.

Governments and countries that have referred to the WPA and who recognized the language of the ICIDH, generally propose the following concepts and topics be included when

designing their program planning:
(a) *impairments* for the study of prevention; (b) *disability* for planning programs in rehabilitation; and (c) *handicap* for assessing human rights and equalization of opportunity. Dr. Chamie stated that regional, and even national comparisons of disability rates may be misleading unless the methodological and conceptual differences between data collection systems are taken into account.

Discussion

Conference participants discussed the efficacy of national population-based surveys. One of the advantages of such surveys is their ability to measure the ICIDH concepts of "impairment" and "handicap" (that is, the interaction of the individual with the environment). Other data collection strategies can be used to measure the community structure itself, thus providing a complementary perspective.

The disability community was urged to move beyond the previous day's debate about prevention and adopt the WPA usage of prevention as it relates to impairment, disabilities, and handicaps. Currently, the community of persons with disabilities is underrepresented in the goals of *Healthy People 2000* precisely because the baseline data are inadequate for setting such prevention goals.

Conference participants reemphasized the importance of documenting the effects of legislative endeavors such as the ADA. Dr. Chamie presented information showing that the number of national population-based surveys and censuses that asked questions about disability increased dramatically during the United Nations' Decade of Disabled Persons.

Session V (Part 2)

Research Strategies for Statistics: Survey Data and Qualitative Research

Moderator:	**Mary Raether,** National Council on Disability
Speaker:	**Carol Howland,** Baylor College of Medicine
Discussants:	**Barbara Altman,** Agency for Health Care Policy Research **Nora Groce,** Yale University

Mary Raether, Member, NCD, introduced Carol Howland, Baylor College of Medicine, who presented a paper written by Dr. Margaret A. Nosek, who was unable to attend.

Summary of Dr. Nosek's Paper

Dr. Nosek's paper, *Research Strategies for Statistics, Survey Data, and Qualitative Research,* argues that the particular strength of qualitative research lies in identifying interrelationships among factors and themes that underlie an issue. She states that qualitative techniques can be extremely useful in examining the impact of disability policy and assessing the degree to which the four broad goals of the ADA are being met. Qualitative approaches can adequately address the complexity and seriousness of minority and cultural issues in disability policy. Qualitative research is particularly well suited for persons with disabilities who are trained researchers because it relies heavily on the inductive and intuitive abilities of the researcher. Finally, qualitative techniques are invaluable in determining the appropriate questions to ask in assessing the effectiveness of disability policy.

Discussants' Comments

Dr. Barbara Altman, U.S. Agency for Health Care Policy and Research, who discussed Dr. Nosek's paper, addressed the tensions between researchers advocating quantitative and qualitative approaches, and made several comments on other topics.

Summarizing Dr. Nosek's paper, Dr. Altman pointed out that qualitative methods are quite useful in policy research and evaluation. She commented that she would like to see the concept of consumer choice more fully examined by qualitative techniques, both within the community of persons with disabilities and in comparison with individuals who are not currently disabled. Qualitative research can also help inform the debate on defining disability nomenclature, incorporating concepts such as "role loss" and the impact of the environment in changing personal and social circumstances.

Dr. Altman expressed concern about Dr. Nosek's selection of subjects for qualitative research in disability. She pointed out that "captive audiences" of individuals with disabilities in homes or centers who are easy to study do not provide a balanced picture of the community of persons with disabilities. Dr. Altman agreed with Dr. Nosek that qualitative and quantitative research techniques should not be seen as competitors but as complementary entities. Qualitative research provides depth, whereas quantitative research provides breadth. When used in tandem (for example, the use of qualitative techniques to design questions used in quantitative surveys), the effect is greater.

On the much broader topic of disability research as a whole, Dr. Altman urged that the field of disability research continue to reach beyond health concerns to include other

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disciplines. At the same time, she stressed the need for an entity (perhaps NCD, perhaps other bodies) to bring resources and people together and disseminate results more effectively.

Dr. Nora Groce, Yale University, affirmed the idea of combining qualitative and quantitative research. Too often, strictly quantitative surveys have little relevance to the lives of persons with disabilities or to policy makers. All disability researchers should ask themselves two questions:

1. What do we need to know about the individual and the individual in the community to design workable programs?
2. How do we communicate those findings to policy makers, advocates, and professional groups?

The field of disability research retains a number of culturally based assumptions, such as the debate over terminology. The quest to find one term that covers the variety of experiences involved in disability does not occur in some other languages and cultures. Indeed, no single word for disability may exist. Language itself changes. Any term chosen to describe disability becomes pejorative after a 10- to 15-year time lag. The issue, then, should not be continual reinvention of terms but education of society.

Historically, research on disability has been focused on the individual. A tremendous need has arisen to look at social, economic, cultural, and community factors, not just at the individual as an isolated consumer. Furthermore, cultural and racial subgroups vary greatly within themselves. Relevant data for all groups are needed as a prelude to designing relevant, appropriate programs.

Qualitative research has existed a long time and does not have to be reinvented. One real strength of qualitative research is its long tradition of defining issues upwards from the grass roots. Of course, no program or policy will suit all individuals. Greater flexibility must be built into research models as well as into policies and programs. Researchers working in the disability field must insist on diversity, both as researchers and as policy makers.

Discussion

Conference participants discussed the need to combine qualitative and quantitative research methods. The combined methods can be used to measure complex concepts such as change resulting from implementation of the ADA. Purely quantitative analyses that attempts to measure the impact of the ADA might well show greater dissatisfaction; qualitative techniques might provide the explanation for that dissatisfaction (For example, increased expectations caused by the passage of the ADA). However, very little funding is available for strictly qualitative research. A possible remedy for this situation is the design of truly interdisciplinary research at the university level that incorporates these and other relevant methods.

Session VI

Research Strategies for Monitoring the ADA

Moderator: **Raymond Seltser,** Agency for Health Care Policy and Research

Speaker: **Mitchell LaPlante,** University of California at San Francisco

Discussants: **David Pfeiffer,** Suffolk University

Carolyn L. Feis, General Accounting Office

Jane West, Jane West & Associates

Dr. Raymond Seltser, Agency for Health Care Policy and Research, Public Health Service, chaired the session. Dr. Seltser introduced Dr. Mitchell LaPlante from the University of California at San Francisco.

Summary of Dr. LaPlante's Paper

Dr. LaPlante's paper, *Assessing the Impact of the Americans with Disabilities Act,* discussed strategies for assessing the ADA and focused on national statistical resources. Dr. LaPlante addressed the data and indicators that are available and appropriate in assessing the population targeted by the ADA (36.1 million Americans are limited in activity by physical or mental impairment) and the goals of the ADA. The paper listed a variety of operationally defined measures tied to each of the ADA's four goals that can be used to measure the ADA's impact over time. Dr. LaPlante also suggested several hypotheses about the potential impact of the ADA and ways to document them, including the Current Population Survey and the Survey of Income and Program Participation. The paper closed with three broad recommendations for current and future data collection.

Dr. LaPlante's Presentation

In his presentation, Dr. LaPlante reiterated the main points of his paper. For purposes of evaluation, the ADA's goals must be operationalized and then measured. Dr. LaPlante postulated three hypotheses about the potential impact of the ADA: (a) the percentage of the working-age population with impairments who are prevented from working should decrease considerably; (b) the job-seeking process should become less onerous to people with disabilities who are not working; and (c) earnings for people with disabilities should improve. Data are needed to measure these trends.

National and subnational trend data on rates of disability and the economic situation of people with disabilities must continue to be collected, analyzed, and disseminated. Dr. LaPlante reiterated his three recommendations for current and future data collection efforts: (a) all federal statistical agencies should incorporate disability measurement into data collection efforts; (b) statistical reports should tabulate information by disability status, where feasible; and (c) the feasibility of a national disability survey should be considered. In the immediate future, the 1993–94 National Health Interview Survey disability supplement should be funded. Congressional appropriations should be sought to fund ongoing collection of disability statistics.

Discussants' Comments

Dr. Seltser then introduced the three discussants, starting with Dr. David Pfeiffer of Suffolk University. Dr. Pfeiffer commended Dr. LaPlante for his analysis of the ADA as social legislation with an emphasis on affirmative action and equality of opportunity.

However, he disputed Dr. LaPlante's assertion that the population of people with disabilities is well defined. Furthermore, existing data sets and nomenclature are seriously flawed, a problem not unique to disability statistics.

Dr. Pfeiffer then turned to the issue of the ICIDH. He criticized the ICIDH on three counts: (a) the offensive term "handicapped" does not appear in the ADA; (b) the ICIDH concerns the diagnosis of disease or illness (which puts the onus of disability on the individual rather than on society), while the ADA is civil rights legislation; and (c) the WHO classifications used in the ICIDH are demeaning, paternalistic, and misleading in their emphasis on departure from the "normal." Disability should be defined on a case-by-case basis because discrimination occurs on a case-by-case basis. The ADA is civil rights legislation and should not be limited by irrelevant definitions.

Dr. Seltser commented that the ADA represents legislation designed to prevent disadvantage, not to prevent impairment.

Dr. Carolyn L. Feis, U.S. General Accounting Office (GAO), challenged conference attendees to move beyond current sources of information and data collection systems to redefine the type of data that can be obtained. Dr. Feis argued that it is not too early to evaluate the impact of the ADA. Not all the goals of the ADA are years away from achievement, nor are all new ways of evaluating the ADA years from realization.

With regard to the issue of inadequate baseline data, Dr. Feis argued that some data do exist. However, existing data can be misleading if appropriate analysis is not made. For instance, the cost of reasonable accommodation is extremely difficult to quantify. Using the example of a power-assisted door, Dr. Feis listed a number of different factors not related to the accessibility of the doors, which may nevertheless affect the cost. She urged researchers to examine all cost data very carefully. Dr. Feis also argued that baseline data are not needed in areas such as employment discrimination because such discrimination is illegal; thus, measuring levels of discrimination is an academic exercise.

Dr. Feis reported that the GAO is currently researching one major goal of the ADA: barrier removal. With regard to architectural barriers, GAO is conducting ongoing research that involves people with disabilities and utilizing the perspective of individual interactions with the environment. GAO will, in the near future, begin research on employment discrimination. With regard to the ADA's requirements under Title I, GAO's scope and methods have yet to be determined. This work could focus on any one of several areas: (a) hiring; (b) accommodations made in the workplace; (c) appropriateness or inappropriateness of dismissals of individuals with disabilities; (d) salary differentials and advancement opportunities in employment, all of which follow the EEOC complaint path; or (e) a number of other possibilities.

Dr. Jane West, of Jane West & Associates, reminded conference participants that the ADA is a civil rights law rather than an entitlement program. With regard to Dr. LaPlante's paper, Dr. West commented that the employment rate of people with disabilities has limited utility as a proxy measure for the effectiveness of the ADA because so many other factors (availability of health insurance, educational levels, recession, etc.) influence the employment status of people with disabilities. Furthermore, researchers should not allow the four goals stated in the ADA's preamble to obscure the purpose of the ADA: ending discrimination.

Dr. West then turned to the question of what influence research has on policy. According to Dr. West's research, staff members, other policy makers, lobbying groups, and personal experience have the most influence on policy makers. The GAO, the Office of Technology Assessment, and the Congressional Research Service are the primary research resources for policy makers in Washington, DC. Social science researchers have played a minimal role in influencing disability policy. Disability policy researchers are obliged to think harder about answering the questions for which policy makers need answers.

Dr. West noted that the single most influential piece of disability-related research in recent years was the Harris Poll. What lessons are to be learned from this? The poll was commissioned by a public-private partnership. Its design allowed people with disabilities to speak directly to policy makers in a way that policy makers could understand. Dr. West urged that the research community invest the time to structure a dialogue with policy makers. The interaction between interest groups and policy research may need to be strengthened.

Dr. West recommended that the federal government provide the impetus for relevant disability policy research. That impetus should not be associated with just one discipline (health, education, rehabilitation, etc.). The impetus should be broad enough to cover the many areas that impact on disability.

Dr. Seltser criticized the academic community for failing to produce policy-relevant research. He noted that a tremendous research potential is available to meet the needs of the federal government if its existence can be communicated to policy makers. The goals of the ADA need to be utilized to provide functional measures that look at disability not as an impairment but as a functional state. Adoption of the ICIDH classification system would allow American researchers to take advantage of research and policy advances already occurring in Europe and other places. The American disability policy field must move beyond the nomenclature dispute and provide research that is both communicable and relevant to policy makers.

Discussion

Participants and panelists debated the question of what constitutes relevant policy research. The suggestion was posed that the dissemination of research results can take a long time but that results eventually reach policy makers. On the other hand, research results often appear in inaccessible formats that policy makers and their staffs are unable to interpret. Interest groups often provide the translation of relevant research into the political process. This link requires further development.

The group briefly discussed the issue of affirmative action. Dr. Feis commented that the ADA only speaks to discrimination among "equally qualified" persons.

Dr. Pfeiffer commented that the disability research community does indeed have a common language with policy makers, and that it is not the ICIDH. He stated that using the ICIDH is self-serving for the medical and health fields because it supports a poor paradigm and crude model. Other participants, arguing that the reaction of some in the disability community to terminology used in the ICIDH blinds them to the value of the ICIDH model, took issue with this contention.

Reports From Breakout Sessions

Moderator: **Harlan Hahn,** University of Southern California

Sessions:

- Issues Related to Special Populations—**Sylvia Walker,** Facilitator
- Emerging Issues—**Mitchell LaPlante,** Facilitator
- Building a Disability Studies Discipline—**Irving K. Zola,** Facilitator
- Creating a Common Nomenclature and Classification—**Scott Campbell Brown,** Facilitator

Dr. Harlan Hahn from the University of Southern California invited reports from the previous day's breakout sessions. Dr. Hahn introduced the breakout facilitators, beginning with Dr. Sylvia Walker, who led the session on Issues Related to Special Populations.

A. Issues Related to Special Populations

Dr. Walker reported that the group began its discussions with an overview of the Monday afternoon conference session regarding the implementation of the ADA from the perspective of minorities with disabilities.

At-Risk Populations

The group identified seven at-risk populations: low-income families, young black males (13–18 years old) with disabilities (for example, youth who are learning disabled or mentally ill), individuals with psychiatric disabilities, individuals whose primary language is not English, individuals with HIV/AIDS, Native Americans and Alaska Natives (excluded from the ADA because of tribal sovereignty), and recent immigrants who do not speak English.

The group listed a number of strategies for researchers interested in at-risk populations:

1. Do not assume that nothing has been done by the target group. At-risk populations are often perceived to have nothing to offer.
2. Ensure that the dissemination of research results/outcomes can be translated into action steps that can benefit the target community.
3. Make sure that the research is done in a culturally sensitive manner.
4. Analyses are often erroneous. The target group should be involved in the design, implementation, analysis, and dissemination of the research.

Discrimination

With regard to discrimination, the group identified a number of issues that affect special populations:

1. The stigma of socially unacceptable behavior causes discrimination.
2. The general population tends to generalize about disability and its impact. People with disabilities in various disability groups are often viewed as homogeneous; very little respect is granted for individual differences and individual capabilities.
3. There is a risk of "tokenism" being applied to persons with disabilities.
4. Greater value is placed on research done by members of the majority culture, a group that tends to receive the largest amount of funding, the best training, and the most attention from publications. More effort must be made to involve special populations in research.
5. Bias occurs—do not listen to what is being said, but rather who is saying it.
6. The vocational rehabilitation system does not code AIDS as a disability, thus creating a barrier to service for persons with AIDS.

Research strategies in the area of discrimination include the following items:

1. Establish varying forums for the dissemination of research done by minority researchers.
2. Establish that all funding should meet strict criteria that demonstrate the inclusion of women and special populations and in particular the community upon which the research is focused.
3. Funding sources should follow up to ensure that criteria are being met.

All research must respect cultural values and strive for more inclusiveness in the research process and its outcomes.

B. Emerging Issues

Dr. Mitchell LaPlante discussed the activities of the breakout session on Emerging Issues (personal assistance services, health insurance, assistive technology, etc.).

Personal Assistance Services

The group emphasized that personal assistance services (PAS) are absolutely essential to meet the goal of independent living. The group felt that the application of the medical model to PAS may impair length of services, the quality of services, and care givers; dominance of the medical model can also disrupt services.

The supply of PAS providers varies from place to place. The qualifications of attendants vary.

Their wages are insufficient and turnover is quick. Incentives are needed to provide attendants with a career path. Choice of attendants (either previously trained or willing to be trained) continues to be a pressing issue. The group discussed the pros and cons of certification of attendants; the group believed that people with disabilities should be empowered to determine the services they need, including the training of attendants and the systematization and professionalization of that training.

Currently, some people with disabilities may have to live in poverty in order to meet Medicaid guidelines for PAS. A national policy of universal access to PAS that maintains choice and autonomy is needed.

The group listed two research priorities in the area of PAS:

1. Solid data are needed on the demand for and costs of PAS, including the costs of not providing PAS.
2. Research is needed to determine how reimbursement for PAS will change the demand for those services. Attention should be paid to how voluntary help and help from family members can be maintained as well as care in respite services.

Health Insurance

In the area of health insurance, the group felt that the policy priority was universal access to a comprehensive plan that covers both acute and long-term services.

The group listed four research priorities in the area of health insurance:

1. Determine how the comprehensive nature of benefits can be maintained while controlling costs.
2. Determine how managed care will affect people with disabilities, particularly in the area of costly emerging technology.
3. Assess what the United States can learn from other nations in terms of managed care.
4. Determine whether private, long-term care insurance plans can be designed so that people can buy protection, and whether such a plan would cover people with disabilities who already need long-term services.

Assistive Technology

In the area of assistive technology (defined as any device or technique that promotes the function of people with disabilities), the group identified the following research priorities:

1. Determine the costs of assistive technology and universal barrier-free design, including the costs of not providing such technologies.
2. Assess how knowledge of assistive technology and universal design can be better disseminated to designers and people with disabilities.

C. Building a Disability Studies Discipline

Dr. Zola reported that the group rejected the idea of disability studies as a subdiscipline of another field. The group also discussed the difficulties of building a multidisciplinary or interdisciplinary disability studies program. These difficulties include lack of funding and organization, as well as the problem of faculty members whose primary loyalties (and career advancement potential) lie in more established disciplines.

Despite the difficulties, group members felt that there were opportunities for dialogue in a multidisciplinary or interdisciplinary context. For such a field to emerge, the group felt it was necessary to include the range of physical, mental, and cognitive disabilities. The dialogue among all these fields must be maintained. Group members suggested a possible national conference on disability studies as well as continuing the dialogue within existing conferences.

In terms of national efforts that can develop and sustain an interdisciplinary field of disability studies, the group made one long-term recommendation: Convene a task force of academics and policy makers to map out priorities for a disability studies discipline.

Among the more immediate responses, the group included the following items:

1. Create an administration on disability.
2. Support undergraduate disability studies.
3. Underwrite a journal on disability studies.
4. Specifically earmark research funds for interdisciplinary disability studies.

Dr. Zola then summarized the group's two primary suggestions:

1. Create disability studies predoctoral fellowships to develop the next cadre of specialists, with particular assistance designed to attract and retain people with disabilities.
2. Create a disability policy center(s), either free-standing or university-based, with a wide range of educational mandates.

D. Creating a Common Nomenclature and Classification

Dr. Brown noted that much of the group's discussion had been repeated in the morning conference session on the ADA. He moved directly to the group's recommendations:

1. Regardless of the nomenclature used, evaluation of progress toward the ADA's goals should occur at the interaction-with-environment ("handicap") level of analysis. For example, in the case of special education, the mind-set that "the problem is in the students" must be abandoned and physical or environmental issues must be addressed. Positive measures of how accommodations can be achieved need to be developed.
2. At the personal level (disability), positive measures of functional capacity are needed. This concept is important not just for rehabilitation purposes but also in evaluating who is covered under the ADA.
3. "Handicap" as a term is extremely controversial.
4. The ICIDH provides a classification system that other frameworks do not have.

Discussion

Mr. Hahn returned to the issues raised during the morning from the perspective of politics and political realities. He pointed out that a common theme in all of the presentations was that discrimination affects all disadvantaged groups in society. He expressed the hope that as individuals understand the ramifications of discrimination, they may work to create alliances and coalitions that will lead to the fulfillment of the ADA's goals through the political process.

Dr. David Gray, from the National Institutes of Health (NIH), offered a number of personal comments and suggestions for research priorities. He reported that NIH sponsors research supplements for people with disabilities at all career levels. However, those supplements are tied to regular research grants and program project awards. Dr. Gray's recommendations included the following points:

1. With regard to PAS, explore different kinds of research and demonstration projects all over the country (perhaps funded by insurance companies or other private sources) to determine the most effective way to train attendants.
2. Make an above-the-line tax credit available for workers who must use PAS, thereby removing that deduction from the medical sphere.
3. Create two sources for PAS attendants. In the first case, allow the Immigration and Naturalization Service to move attendants to the category of "underrepresented" professions, thereby easing their entry into the United States. Create a second

source by requiring vocational education curricula to include training for attendants—a policy that would then flow to local school districts.

4. In all research, do modeling that demonstrates how much a particular approach will save for specific populations.

Dr. Donald Galvin of the Washington Business Group on Health recommended, as a model for other federal agencies, the activities of the National Institute for Mental Health that provides funds for university-based interdisciplinary centers examining the economics of mental health. A participant noted that the U.S. Department of Education's Office of Special Education Programs is currently evaluating state systems contracts and compiling data and policy issues related to civil rights and health data for students with disabilities.

One participant stated that cost-benefit analyses of PAS must be supplemented by qualitative evaluation of these services. Also, the alternative costs of institutionalization should not be ignored in the data collection.

Participants then re-explored the issue of prevention of primary disabilities. Whereas some participants felt very strongly that disability is a functional limitation having strong negative consequences for the individual and family, others maintained that individuals with disabilities are part of a minority group subject to discrimination and therefore at risk of being eliminated through primary prevention.

A plea was made for both sides to compromise on the issue of the ICIDH. It was pointed out that there are many different qualitative and quantitative ways to measure the impact of the ADA. Only through a combination of methods will researchers be able to converge on what progress is being made.

A participant suggested that the relationship between individuals with disabilities and society, as well as other political, philosophical, and ethical issues being debated at the conference, cannot be fully explored without the perspectives of the humanities disciplines. Thus, support must be found for research on these issues that would be conducted by scholars in the humanities. The philosophical approach, it was noted, has been addressed (using the ICIDH) in Sweden and Finland.

Session VII

Furthering the Goals of the ADA: Disability Policy Research—Where Do We Go From Here?

Moderator: **Anthony Flack,** National Council on Disability

Speaker: **Irving K. Zola,** Brandeis University

Dr. Zola commented that it is too soon to tell whether this conference will be a watershed event in the evolution of disability policy. Clearly, the conference is a meeting of minds among policy makers and disability researchers as well as a forceful attempt to articulate the diverse voices of the disability community in the formulation of research and policy. Dr. Zola sought to provide some context by offering a brief history of the role of people with disabilities in the formulation of disability-related research.

Dr. Zola traced the evolution of American disability policy from the Civil War through the present. In the 1980s, persons with disabilities entered an age of empowerment. The hallmarks of this latest period are clear: long-term demographic realities, including an aging population, and the challenges of new conditions such as AIDS, Alzheimer's disease, and learning disabilities; emergence of a disability research constituency; the appearance in print of the voices of people with disabilities; a shift away from pejorative descriptions of disability; emergence of the first national attitudinal survey of people with disabilities about themselves; alliances with other groups; increasing visibility and activism of people with disabilities; and development of a political constituency of people with disabilities.

Dr. Zola then offered a number of reflections on the conference. Almost all speakers emphasized that disability is anything but a singular, unidimensional phenomenon. Disability is not a status but an ever-changing characteristic. While some progress has been made in including the physical, social, economic, and political environments in conceptions of disability, more work must be done to create models and measures of disabling environments. The individual experience of disability still receives too much emphasis.

The notion of disability pride and culture, particularly within the deaf community, is a new trend that confronts researchers. Another aspect of this notion is the fact that some types of assistive technology may indeed enhance performance beyond the capabilities of those who are not disabled.

Multicultural diversity, an issue repeatedly addressed by conference speakers, remains an issue for disability researchers. This issue is best addressed on a small scale at the local level. Research must be designed with an appreciation for diversity within racial and ethnic groups themselves, with no assumption of homogeneity.

Dr. Zola noted that the voices of older people and of women had been surprisingly silent during the conference. He urged that these communities not be lulled into complacency by recent progress. He also noted that statistical representation will not assure that the voice of an oppressed minority is heard. People with disabilities must continue to actively articulate and advance their own concerns.

Summary and Conclusions

Sandra Swift Parrino, Chairperson, National Council on Disability

During the last three days, the community gathered at this conference has achieved great progress toward establishing a research agenda for the 1990s to further the goals of the Americans with Disabilities Act. The ideas, energy, good humor, and hard work that have been expressed here are a tribute to all of you who participated in this conference. Closing a conference like this is thus a difficult task, because I hate to see you all go.

It is important to understand, however, that this closing marks not an end to a conference but rather an important step in a process—a process to make the Americans with Disabilities Act work for all Americans. What this conference has stressed is that research has the potential to be an important tool to implement the ADA. Moreover, our participants have provided us with some concrete suggestions on how to use this tool, not to be an end unto itself, but rather to be a means toward an end.

I believe that this conference has achieved the goals outlined in the opening address. These goals were to initiate a dialogue on furthering the goals of the ADA through disability policy research, to identify the resources and infrastructures available to enhance the process, and to articulate steps we can take to foster disability policy research.

Turning to the first goal, I think we all can agree that we have enjoyed quite a dialogue during the last 3 days. Our speakers highlighted several important issues. John Dunne turned our attention to the issues of barriers—legal, physical, and attitudinal barriers. In his keynote address, he urged that we turn our attention to efforts that will have immediate value for persons with disabilities. He argued that litigation monitoring, policy development, and education and technology issues need to be addressed through disability policy research. These themes were repeated throughout the conference.

Both Simi Litvak and Drew Batavia provided us with an assessment to indicate that research is an area that, in the past, has been viewed with suspicion by persons with disabilities. There appeared to be general agreement with Simi Litvak's point that our focus should not be on an evaluation of the ADA, but rather on its implementation. Likewise, Drew Batavia's concern that research needs to emphasize process issues related to full inclusion was echoed by others at the conference. All agreed that persons with disabilities need to be included in all stages of the research process. However, the exact role of persons with disabilities has yet to be defined. The participatory model recently developed by NIDRR is viewed as a potential major breakthrough in involving persons with disabilities in the process.

In the session on special populations, Paul Leung noted that we need to be more sensitive to cultural concerns. Sylvia Walker raised the issue of multiple jeopardy, documented by the higher prevalence of disability in minority communities.

Yesterday morning, the speakers at the session on shaping an interdisciplinary field of disability policy research highlighted several issues. Andy Schoenberg asked us to think about how the trickle-down of technology can be improved. David Dean urged that economic studies move beyond the traditional biases of cost-benefit analyses. Gerben DeJong noted that health professions are varied and that these different viewpoints need to be considered in policy research. Irv Zola noted the tension between advancing a separate field of disability policy studies and advancing disability as a subunit of all appropriate disciplines. Susanne Bruyère argued that the vocational rehabilitation field needs to move towards participatory models.

In our session on classification, Michel Thuriaux argued that the ICIDH has proved useful as a tool for improving the quality of life for persons with disabilities in other countries. For example, he noted that it proved useful in developing a policy for cost reimbursement in France. Bill Frey extended the use to the United States in developing an assessment tool for children with disabilities. Both speakers urged that we keep in mind that the "handicap" classifications are not classifications of people, but rather of circumstances involving quality of life barriers.

Our session on quantitative research gave us Lois Verbrugge and Michele Adler, who turned our attention to the importance of this research to evaluation. Lois Verbrugge reminded us that disability is a process. Michele Adler urged funding for an important effort, the 1993–94 Disability Supplement to the National Health Interview Survey. In the qualitative research session, Carol Holland argued that open-ended studies give us a depth of meaning and detail unavailable from quantitative research. Most agreed that these two types of studies are both needed and complement each other.

This morning, Mitch LaPlante pointed out that ending discrimination is the primary goal of the Americans with Disabilities Act. He urged that disability become a standard item in all federal data collection efforts. Three steps he suggested were (a) funding for the Health Interview Survey Disability Supplement, (b) planning a continuing disability survey, and (c) a longitudinal study of disability.

In his summary remarks, Irv Zola noted that laws have always been important for persons with disabilities. Public policy has slowly moved away from medical control; we are moving toward an age of empowerment.

Our speakers served us well by initiating a dialogue. Some issues were not resolved here. While persons with disabilities must be involved in the process, the extent of their participation is yet to be determined. The proper mix between quantitative and qualitative research for fostering policy must be further explored. Clearly, use of the term "handicap" in the ICIDH is a concern for many people.

However, by accomplishing its second and third goals, this conference has given us sound guidance on building infrastructure and establishing priorities. Let us turn our attention first to infrastructure issues.

There currently are a variety of federal agencies concerned with disability policy research. I will not name them all, because there are so many and I do not want to leave any out. However, it is clear that the efforts of these agencies need to be coordinated. The National Council on Disability stands ready to serve as a vehicle for coordinating these efforts.

However, other mechanisms are also important. NIDRR's Interagency Committee on Disability Statistics has long served as a vehicle for bringing together data producers and users within the government. It has been very involved in urging U.S. involvement in the ICIDH process. Federal agencies need to participate in this group and take advantage of its efforts.

There are a variety of other interagency committees involved in aging and health issues. Agencies interested in disability policy research should participate to ensure that disability becomes a consideration in all major federal policy decisions.

Turning last to concrete suggestions, the following recommended actions form the basis of a plan for fostering disability policy research in the 1990s. The first are short-term steps that we can immediately take:

1. Establish a set of disability indicators similar to economic indicators and *Healthy People 2000*.
2. Continue involvement in the ICIDH. The United States must be involved in this process.

3. Fund the 1993–94 Disability Supplement. This will establish any baseline data needed.

There are also several long-term actions we should begin to implement:

1. Involve persons with disabilities in the research process. This means that special populations must also be involved.
2. Develop positive measures of functional capacity and accommodation. We must move from a medical to a disability model.
3. Develop mechanisms for disseminating research in forums that policy makers will use. Examples of such mechanisms are the Harris Poll and Office of Technology Assessment studies.
4. Develop mechanisms for integrating qualitative and quantitative study results.
5. Encourage research in the area of personal assistance services. Such research should focus on empowerment, attendant training, and service delivery.
6. Encourage research in the area of health insurance. Such research must focus on service delivery to persons with disabilities.
7. Focus on developing a field of disability policy.

The National Council is very grateful indeed for your participation during this conference. Special thanks have been given during the 3 days we have been here, but once again I would like to thank Irv Zola—he has very little free time and did give us some extra time; Mitch LaPlante, for planting the idea; Gerben DeJong; Gerry Hendershot; Ray Seltser; Kate Seelman (who was on the staff of the Council); my assistant, Janis O'Meara, (who all of a sudden got all of it loaded onto her shoulders, and has done a wonderful job); and Jacquie Sheehey from Walcoff & Associates, Inc. (they have done a magnificent job and her whole staff should be commended). We certainly want to thank the sign language interpreters. I thank all the members of the National Council and Scott Brown, who has worked at two jobs constantly, both at OSERS and with the Council. If I have left anyone out, I do apologize.

From the heart, the best way for me to wind up my remarks is to note that the Council looks at these problems from a very pragmatic viewpoint. We look at the problems facing a person with a disability. I am motivated on a regular basis by my own son, who is severely physically disabled. I mention him because he has taught me the problems that face many people with disabilities. These problems are what continue to motivate so many of us. He is completely independent because he has a personal assistant. When he does not have that personal assistant, he is totally dependent. He is a very good example of somebody who went through the educational system and saw the segregation in that system. He is a person who needs health insurance, personal assistance, and assistive technology. These are issues that we hope you all will help us with because they are very critical issues that the ADA does not address. So many people who need personal assistance, for example, or who need insurance, may never even face discrimination because they cannot even get out of their homes. So the ADA may never really affect them at all.

We hope that you will assist us with your expertise and your commitment and your skills in what we hope is expressed in the title of this conference, *Furthering the Goals of the ADA Through Disability Policy Research.* We need your data and your research to back up the policy decisions that have to be made and presented to the policy makers. So we are depending on you. We are here to assist you in any way that we can. We thank you very, very much for coming. We are very grateful for your leadership, which has been so outstanding for so many years. Thank you for coming and Godspeed.

Section II: Conclusions and Recommendations

Background

The conference produced literally hundreds of suggestions for research on specific topics. Some of these suggestions were included in the recommendations of the eight breakout sessions. Many more appeared in the papers written by conference presenters.

As might be expected, numerous suggestions for disability research extended beyond the civil rights scope of the ADA. Indeed, some participants discussed whether the four major goals of the ADA (equality of opportunity, full participation, independent living, and economic self-sufficiency) can or should be measured at this stage. Several participants stressed the need to differentiate between measuring the current ADA compliance and the future ADA outcomes.

In addition to suggestions for specific studies, conference participants developed a number of recommendations concerning the research process itself. They addressed issues ranging from the cultural and philosophical perspectives of disability policy researchers to the political and social climate in which research results are received. Some participants believed that the advocacy roles of some disability researchers may unduly influence their research design and results. At the same time, calls were made for closer collaboration with advocacy groups of all types to bring disability research results and disability issues to greater public prominence. Underlying the discussion of advocacy was a perception that disability policy researchers have not been entirely successful in satisfying the needs of interested policy makers.

In terms of research methodologies, conference participants generally agreed that a broad array of techniques would give the best picture of disability. Qualitative and quantitative methodologies were recommended.

Conference participants emphatically disagreed with one another about the usefulness of the ICIDH as a framework for conducting research and analyzing results. Indeed, conference participants seemed about evenly divided among those who believe individuals with disabilities experience functional limitation and those who consider individuals with disabilities members of an oppressed minority group. These philosophical differences about the nature of disability naturally influenced the differing responses to issues raised during the conference.

One area of apparent agreement among conference participants was the importance of seeing the individual with a disability as a part of society as a whole rather than as an isolated element. At the same time, participants stressed the empowering nature of concepts such as individual choice and autonomy for people with disabilities.

Recommendations listed without attribution are the work of more than one person, developed in either the breakout sessions or the conference plenary sessions.

This section is broken down by topic into the eight plenary sessions of the conference and the eight breakout sessions for easy reference.

A. Conference Plenary Sessions

Session I—
Disability Research and Enforcement of the ADA

Mr. John R. Dunne

Mr. John R. Dunne, Assistant Attorney General, Civil Rights Division, U.S. Department of Justice, noted several critical areas that have been neglected by researchers: (a) litigation monitoring, (b) policy development, (c) education, and (d) technology. Related issues on which research should be focused include discrimination in standardized testing procedures and environmental illness and its possible links to disabilities.

Training and monitoring concerns also exist, according to Mr. Dunne, who suggested the following research and training priorities:

1. Improve the training of architects and attorneys to raise the ADA "literacy level" in these two professions.
2. Document the activities of those calling themselves experts on the ADA who play on the fears of small business owners.
3. Monitor state and local compliance with Title II.

Session II (Part 1)—

Putting Research to Work for the Realization of the Goals of the ADA: The Perspective of the Community of Persons With Disabilities

Dr. Simi Litvak

In her paper, Dr. Simi Litvak offered a number of recommendations concerning disability policy research:

1. The goals of a particular study must meet the needs of the particular stage of the policy process life cycle for it to be useful to policy makers.
2. During the policy formulation stage, policy makers look for research on the problem, past solutions, and evaluation of policy options and trade-offs.
3. During the policy execution phase, policy makers look for research on the implementation process, sites, costs of implementation, how the stakeholders feel, and problems with implementation (the current stage in the policy life cycle of the ADA).
4. During the final stage in the policy process, policy makers are interested in research on accountability and quality.

Dr. Litvak also listed important implementation issues and questions for assessing the progress of the ADA:

1. Track compliance.
2. Evaluate the nature and quality of technical assistance being provided to better business bureaus, hotel associations, university administrators, and others.
3. Document and disseminate models that demonstrate good solutions.
4. Conduct marketing research on what best "sells" the ADA, disability rights, and integration.
5. Research additional solutions to technological and mechanical issues.
6. Conduct access guidelines research covering a wider range of persons with disabilities.
7. Define universal design parameters.
8. Assess the barriers inherent in and accommodations made to standardized testing procedures for people with disabilities.
9. Research methods (tax credits, grants, vocational rehabilitation funding, etc.) of spreading the costs of necessary accommodations among the different players.
10. Further assess the needs of people with disabilities (e.g., people with psychiatric disabilities in the workplace, in medical settings, and in educational facilities) whose accommodation needs were not considered in any depth by the writers of the ADA.

Mr. Andrew Batavia

In his paper, Mr. Andrew Batavia listed a number of relevant disability policy research questions that should be asked:

1. Is the ADA being implemented successfully? What have been its effects? What are the model practices used by covered entities? How has technical assistance been useful and how can it be improved?
2. Which populations are served by disability programs? Is the ADA serving racial and other minorities with disabilities adequately? How can their needs be better addressed?

3. How should researchers define populations at high risk of disability or secondary disability (e.g., medical complications)? What programs and interventions can be developed and implemented to reduce the risk of disability or secondary disability?
4. What is the unmet need for personal assistance services? How many people are currently receiving unpaid personal assistance services from relatives and friends who would demand paid services if a national program were established?
5. What are the unmet needs for assistive devices? How much money would the satisfaction of such needs cost? How much would assistive technology decrease institutionalization, enhance employability, and increase ability to live independently?
6. What are the unmet health care needs and costs of people with disabilities by impairment, functional status, and demographic variables? How can society efficiently meet their needs while reducing costs? How would the various health care reform proposals likely affect people with disabilities?
7. What are the unmet needs of people with disabilities with respect to education and training, employment, housing, telecommunications, and transportation? How can society efficiently meet their needs while reducing costs?
8. How can researchers best measure "handicapping" environmental variables (e.g., transportation and architectural barriers), incorporate such variables into functional status measurement instruments, and apply them appropriately in policy contexts?
9. How can researchers best define and operationalize concepts such as "quality of life" and "independence" for people with disabilities? How can these concepts be applied in policies and programs for people with disabilities?
10. What are the best ways to finance and deliver assistive devices, personal assistance services, and adequate health insurance for people with disabilities?
11. How do the various disability laws and policies interact with each other? Do they at times conflict and create inadvertent disincentives to work or to live independently?

According to Mr. Batavia, an effective public policy on disability policy research would recognize the appropriate roles of advocates, researchers, and policy makers and the importance of meaningful and appropriate participation by people with disabilities in the research and policy-making process. Advocates, researchers, and policy makers should ask representatives of the community of people with disabilities, including underrepresented people with disabilities, the following questions in allocating scarce research funds:

1. What are the specific research needs of persons with disabilities?
2. Which specific subpopulations of people with disabilities will benefit from this research?
3. How will it ultimately affect their lives?

During Session II, several suggestions for improving the quality of disability policy research were made:

1. Advocate after conducting research, not before.
2. Train more researchers with disabilities.
3. Take steps to bring disability policy research into mainstream scientific literature, which will necessarily dictate the improvement of disability policy research.
4. Establish objectivity by truthfully describing research methods and

assumptions and by separating findings from recommendations.

Session II (Part 2)—

Putting Research to Work for the Realization of the Goals of the ADA: The Perspective of Minorities and Other Underserved Populations

Dr. Paul Leung

Working from the perspective that the ADA does not account for racial, ethnic, or cultural differences and that lack of sufficient data excludes such groups from the policy process, Dr. Paul Leung offered several research questions related to the ADA's impact on racial or ethnic minorities:

1. Are outreach efforts, as presently practiced, effective? If not, what are some ways in which outreach efforts can be improved?
2. If persons understand the legislative intent of the ADA, are they using it? If not, why?
3. Are there more effective models that may allow persons who have not participated to do so?

Dr. Sylvia Walker

Dr. Sylvia Walker assessed current research efforts to document disability in racial or ethnic minority communities:

1. Relatively little research has been conducted that examines specific variables relative to ethnicity, disability, health status, income, education, geographic location, and other relevant factors.
2. Research that provides information about Asian Americans, Native Americans, Pacific Islanders, and other underrepresented groups with disabilities is needed.
3. AIDS and other disabilities are more prevalent in minority communities than in other cultural groups in the United States. Therefore, the incidence of health care problems, illness, and other sociological challenges make the need for increased rehabilitation policy research critical.

Dr. Evelyn Davis

Dr. Evelyn Davis offered the following recommendations:

1. The disability community must insist on further research into the developmental disabilities of children born with alcohol and drug exposure and HIV and the impact of those disabilities on parents, educators, and service providers. Researchers must be trained to cope with the special needs of these populations.
2. Researchers must be trained to elicit data with the use of culturally appropriate techniques.

Session III—

Shaping an Interdisciplinary Field of Disability Studies Responsive to the Goals of the ADA

Dr. David Dean

Dr. David Dean outlined a disability research agenda for employment policies in light of the ADA:

1. Determine the costs of reasonable accommodation and assistive technology to businesses, using terms as explicit as possible.
2. Case studies at the company level can help determine the hidden costs of compliance with the ADA.
3. Controlled experimentation to determine discriminatory hiring practices can be used to encourage businesses to comply with the ADA.
4. In general, businesses may be more willing to comply with the ADA when owners are convinced that it is in their rational interest to do so. Methods such as measuring reduced costs traceable to compliance with the ADA in areas such as lower workers' compensation expenditures and reduced long-term disability benefits may convince owners to comply.

5. Businesses must be made aware of the costs of noncompliance with the ADA.
6. Researchers should look at the costs versus benefits of return to work programs, estimates of which have been wildly inflated by businesses.

Dr. Gerben DeJong

Dr. Gerben DeJong listed a number of concrete steps that can be taken to develop a disability and health policy research capacity:

1. Educate members of health-related professions.
2. Locate an appropriate academic home for the field. Candidate homes include graduate programs in public policy and schools of public health. Noncandidates include clinical disciplines and rehabilitation counseling centers.
3. Develop a curriculum.
4. Develop graduate and postdoctoral research opportunities (course papers, graduate research assistantships, master's and doctoral research, and research internships).
5. Recruit faculty members with disabilities.
6. Recruit students with disabilities.
7. Create postgraduate training for people knowledgeable about disability issues who need research and statistics training and for people from other disciplines who need to be educated on the values and concepts of disability rights.
8. Create disability and health policy research centers.
9. Support journals and professional organizations as outlets for publications.

In his paper, Dr. DeJong also listed the resources needed for such an undertaking.

Dr. Susanne Bruyère

Dr. Susanne Bruyère listed three implications of the ADA for research in vocational rehabilitation:

1. Enhanced participation in research by persons with disabilities.
2. Collaborative research with businesses and labor unions.
3. Research on impact with other interfacing legislation.

According to Dr. Bruyère, interdisciplinary interfaces are needed with the economics, engineering, health, and social policy fields.

Dr. Mary Chamie

Dr. Mary Chamie recommended two rules for interdisciplinary research and made a suggestion about controlled experimentation:

1. Build in full exchange across the disciplines.
2. Include measures that ensure that the research is fully interdisciplinary, such as internships that allow individuals from one discipline to share the activities of another.
3. With regard to controlled experimentation in the disability field, researchers should also consider controlling the environment (width of doors, height of steps, etc.) in any experiment, not just the participants.

Session IV—

Strategies for Adopting Common Nomenclature That is Responsive to the Goals of the ADA: National and International Experiences

Dr. Michel Thuriaux

Dr. Michel Thuriaux offered a single broad recommendation in the area of nomenclature:

The careful use of collectively agreed-upon nomenclature will help the international community address the increasing issues of disability.

Dr. William Frey

On the national level, Dr. William Frey also endorsed the acceptance of a common nomenclature:

1. Agreement on terminology and on a model of "disablement" will lead to better data collection, which will in turn affect the adoption of policies concerning people with disabilities.
2. ICIDH provides a unifying terminology and a model for disability researchers that meshes with the goals of the ADA.

Dr. Donald Patrick

Dr. Donald Patrick recommended studies such as those funded by the National Institute for Mental Health in the area of mental health as models for local, area-based studies.

Session V (Part 1)—

Research Strategies for Statistics: Survey Data and Quantitative Research

Dr. Lois Verbrugge

Dr. Lois Verbrugge's five recommendations for researchers (all of which are discussed in greater detail, including subcategories of recommendations, in her paper) included the following items:

1. Efforts to increase similarity in disability concepts and definitions should continue, but not at the expense of furthering science itself. In the absence of consensus, clarity is the top priority.
2. By illuminating the disablement process for various chronic conditions and across ages from young to old, researchers will obtain powerful implications for clinical care and health insurance programs about points and strategies for interventions that work.
3. Population surveys and the empirical research that they generate will not directly reveal the ADA's success, but their information is invaluable for tracking the nature of disability in the population.
4. The disability experience must be measured in its own terms and at its own pace. Some methodological research is needed to help survey designers choose apt language and apt time windows.
5. In the current scientific climate (which is likely to continue), the federal government must take principal responsibility for generating large-scale disability surveys and for providing funds for analysis.

Ms. Michele Adler

Ms. Michele Adler proposed strengthening existing statistical surveys to include more information about disability:

1. Ensure that disability data are collected in the Year 2000 Decennial Census by participating in the process now.
2. Ensure that disability data are collected routinely when the annual Survey of Income and Program Participation is redesigned starting in 1995.
3. Ensure that disability data are expanded and collected routinely when the annual Current Population Survey (CPS) is redesigned starting in 1995.
4. Ensure that the 1994–1995 National Health Interview Disability Survey can begin as scheduled.
5. Ensure that disability is a major issue of the annual National Health Interview Survey (NHIS) when it is redesigned starting in 1995.

Session V (Part 2)—

Research Strategies for Statistics: Survey Data and Qualitative Research

Dr. Nora Groce

Dr. Nora Groce stated that all disability researchers should ask themselves two questions:

1. What do we need to know about the individual and the individual in the community to design workable programs?

2. How do we communicate those findings to policy makers, advocates, and professional groups (physicians, etc.)?

Session VI—

Research Strategies for Monitoring the ADA

Dr. Mitchell LaPlante

Dr. Mitchell LaPlante offered three long-term recommendations for future data collection efforts:

1. All federal statistical agencies should incorporate disability measurement into data collection efforts.
2. Statistical reports should tabulate information by disability status, where feasible.
3. The feasibility of a national disability survey should be considered.

In the immediate future, Dr. LaPlante also recommended that—

1. The 1993–1994 National Health Interview Disability Survey should be funded.
2. Congressional appropriations should be sought to fund ongoing collection of disability statistics.

Dr. Jane West

Dr. Jane West offered three recommendations for monitoring the ADA:

1. The federal government should provide the impetus for relevant disability policy research.
2. This impetus should not be associated with just one discipline (health, education, rehabilitation, etc.).
3. This impetus should be broad enough to cover all the various areas that have an impact on disability.

Session VII—

Furthering the Goals of the ADA: Disability Policy— Where Do We Go From Here?

Dr. Irving Zola

Dr. Irving Zola offered a number of reflections on disability research:

1. Disability is best conceptualized not as a status but rather as a characteristic, and a changing one at that.
2. There must be a recognition of the continuous rather than the dichotomous nature of disability.
3. Researchers must create measures and models of disabling environments rather than focus on the individual person as the basic unit of analysis.
4. The positive aspects of disability (e.g., deaf culture, assistive devices that enhance prior lost function) should be captured by disability researchers.
5. The dynamics of culture can best be captured in small-scale, local studies designed with an appreciation for diversity within racial and ethnic groups themselves and with no assumption of homogeneity.
6. Persons experiencing the entire range of disabilities from all racial, ethnic, gender, age, socioeconomic, and other groupings should be actively involved in the disability research and policy-making process.

Summary and Conclusions

Mrs. Sandra Swift Parrino

Looking back over the discussions during the conference, Mrs. Sandra Swift Parrino suggested three short-term steps to foster disability policy research in the 1990s:

1. Establish a set of disability indicators.
2. Continue involvement in the ICIDH.
3. Fund the 1993–1994 NHIS Disability Supplement.

Mrs. Parrino also listed a series of activities for the long term:

1. Involve persons with disabilities in the research process.
2. Develop positive measures of functional capacity and accommodation.
3. Develop mechanisms for disseminating research in forums that policy makers will use.
4. Develop mechanisms for integrating qualitative and quantitative study results.
5. Encourage research in the area of personal assistance services.
6. Encourage research in the area of health insurance.
7. Focus on developing a field of disability policy.

B. Breakout Sessions

Equality of Opportunity

Members of the breakout session identified six general issues that extend across the specific areas of employment, education, public accommodations, government services, and telecommunications to affect equality of opportunity:

1. Access to health care.
2. Access to personal assistance services.
3. Monitoring compliance with the ADA.
4. Defining and achieving equality of opportunity.
5. Increasing public awareness of the ADA and the right to equality of opportunity under the ADA.
6. The need for basic data on equality of opportunity in employment, education, etc.

Research priorities affecting equality of opportunity were identified by category:

Employment

1. How have employers responded to the ADA? Have they determined their responsibilities under the ADA? How? How have they responded to those new responsibilities?
2. What are the work disincentives associated with SSI, SSDI, and the lack of adequate health insurance for people with disabilities?

Education

1. What are the best models of special education and integration of students with disabilities into mainstream classes?
2. What programs and models work best for transition from school to work?

Public accommodation

1. Identification of unmet needs.
2. Determination of the effectiveness of accommodations such as architectural modifications.

Government services

1. How do differing definitions of disability in federal programs interact with one another to affect equality of opportunity for government services?
2. How can interpretations of the ADA be coordinated across states?

Telecommunications

1. How do public carriers train personnel to meet standards of effective service?
2. How should systems designers be trained in considering accessibility factors?

Full Participation

During this breakout session, it was determined that any research conducted on full participation must include these research priorities:

1. Determine the quality and degree of participation.

2. Institute freedom of choice in considering whether to participate or not.
3. Are separate but equal arrangements truly equal and do they truly allow full participation?
4. Barriers to participation are multiple—the ADA is only a guideline, not a guarantee to full participation.
5. Barriers to full participation arise if an individual does not know what opportunities are available to him or her.
6. The dissemination of information about the ADA is incomplete, meaning that barriers to full participation remain for individuals who are not familiar with the ADA.
7. Who makes up the reference group by which full participation is judged? How can participation be evaluated across the spectrum of disability?
8. The current national debate over health care obviously affects people with disabilities. Immediate research is needed on the effects of the different proposals on people with disabilities, particularly the proposals for prevention of disabilities.
9. People with disabilities are not isolated from society but are a part of the whole, meaning that full participation should be considered from both individual and societal perspectives.
10. All of the goals of the ADA are extremely complex and require input from people with disabilities, philosophers, and people who study ethical issues using quantitative, qualitative, and participatory research methodologies.

Independent Living

Members of the breakout session noted that the community of persons with disabilities and disability researchers are moving from a medical paradigm to a disability paradigm. This movement presents an obvious question: How is research based on this new paradigm translated into policy? Both quantitative and qualitative research methodologies can contribute to this debate.

Research priorities with respect to independent living include the following items:

1. Operationalize what "independent living" means and test its implications.
2. Study the implementation of the ADA now and its outcomes later.

Economic Self-Sufficiency

Economic self-sufficiency was defined in this breakout session as follows:

> *An individual is economically self-sufficient if that individual earns or can earn enough to meet his or her basic life needs. A household is economically self-sufficient if someone in that household (or the household collectively) earns enough to meet the household's basic needs.*

Research priorities in the general area of economic self-sufficiency include the following items:

1. Establish the need for baseline national statistics on economic self-sufficiency for people with disabilities.
2. Identify federal agencies that will support such a survey.
3. For people with disabilities who meet the various federal eligibility criteria (such as those for Social Security and SSDI), what are the factors that separate those who work from those who do not work?
4. Examine upward mobility within jobs for persons with disabilities.
5. Examine the quality of training provided to persons with disabilities. Determine what succeeds in promoting economic self-sufficiency.
6. Compare lifetime earnings and upward mobility for people with various

disabilities with those of the general population…

7. Establish the need for a variety of integrated programs.
8. Establish the need for more stringent evaluations of programs intended to promote economic self-sufficiency among people with disabilities. Define success for such programs.
9. Determine what answers are needed by policy makers.
10. Extend research to examine economic self-sufficiency issues beyond the working age of persons with disabilities.
11. Document those programs and policies that are now successful.
12. Explore ways to better utilize existing data.

A member of the audience suggested a thirteenth priority:

13. Document the importance of reasonable accommodation in the workplace in enhancing the economic self-sufficiency of workers.

Issues Related to Special Populations

At-Risk Populations

Members of the breakout session identified seven at-risk populations: low-income families, young black males (13–18 years old) with disabilities (e.g., learning disabled, mentally ill), individuals with psychiatric disabilities, individuals whose primary language is not English, individuals with HIV/AIDS, Native Americans and Alaska Natives (excluded from the ADA because of tribal sovereignty), and recent immigrants who do not speak English.

Strategies for researchers interested in at-risk populations include the following items:

1. Do not assume that nothing has been done by the target group. At-risk populations are often perceived to have nothing to offer.
2. Ensure that the dissemination of research results or outcomes can be translated into action steps that can benefit the target community.
3. Make sure that the research is done in a culturally sensitive manner.
4. Analyses are often erroneous. The target group should be involved in the design, implementation, analysis, and dissemination of the research.

Discrimination

Research strategies in the area of discrimination identified by the session participants include the following items:

1. Establish alternative forums for the dissemination of research done by minority researchers.
2. Establish that all funding should meet strict criteria that demonstrate the inclusion of women and special populations and, in particular, the community upon which the research is focused.
3. Funding sources should follow up to ensure that criteria are being met.
4. All research must be designed to respect cultural values and strive for more inclusiveness in the research process and its outcomes.

Emerging Issues

PAS

PAS are absolutely essential to meeting the ADA's goal of independent living. The members of this session identified the following research priorities in the area of PAS:

1. Solid data are needed on the demand for and costs of PAS, including the costs of not providing PAS.
2. Research is needed to determine how reimbursement for PAS will change the demand for those services. Attention should be paid to how voluntary help and help from family members can be

maintained as well as care in respite programs.

3. Explore different kinds of research and demonstration projects all over the country (perhaps funded by insurance companies or other private sources) to determine the most effective way to train attendants.
4. Make an above-the-line tax credit available for workers who must use PAS, thus removing that deduction from the medical sphere.
5. Create two sources for PAS attendants. In the first case, allow the Immigration and Naturalization Service to move attendants to the category of underrepresented professions, thus easing their entry into the United States. Create a second source by requiring vocational education curricula to include training for attendants, a policy that would then flow to local school districts.
6. In all research, utilize modeling that demonstrates how much a particular approach will save and for which populations.

Health Insurance

In the area of health insurance, an overarching policy priority determined by the group was universal access to a comprehensive plan that covers both acute and long-term services.

Research priorities in the area of health insurance were determined by the group as follows:

1. Determine how the comprehensive nature of benefits can be maintained while controlling costs.
2. Determine how managed care will affect people with disabilities, particularly in the area of costly emerging technology.
3. Assess what the United States can learn from other nations in terms of managed care.
4. Determine whether private, long-term care insurance plans can be designed so that people can buy protection and whether such a plan would cover people with disabilities who already need long-term care services.

Assistive Technology

In the area of assistive technology (defined as any device or technique that promotes the function of people with disabilities), the following research priorities were identified by the group:

1. Determine the costs of assistive technology and universal barrier-free design, including the costs of not providing such technologies.
2. Assess how knowledge of assistive technology and universal design can be better disseminated to designers and people with disabilities.

Building a Disability Studies Discipline

Despite obvious difficulties, opportunities for dialogue exist in a multidisciplinary or interdisciplinary context that includes the range of physical, mental, and cognitive disabilities. Dialogue among all these fields must be maintained. As a result, a possible national conference on disability studies was suggested by breakout session members, as was combining the dialogue within existing conferences.

In terms of national efforts that can develop and sustain an interdisciplinary field of disability studies, one long-term recommendation was made:

Convene a task force of academicians and policy makers to outline priorities for a disability studies discipline.

More immediate responses include the following items:

1. Create an administration on disability.
2. Support undergraduate disability studies.
3. Underwrite a journal on disability studies.

4. Specifically earmark research funds for interdisciplinary disability studies.

Overarching suggestions of particular importance include the following two items:

1. Create predoctoral fellowships in disability studies to develop the next cadre of specialists, with particular assistance designed to attract and retain people with disabilities.
2. Create a disability policy center(s), either free-standing or university-based, with a wide range of educational mandates.

Dr. Donald Galvin recommended the activities of the National Institute for Mental Health in funding university-based interdisciplinary centers, which look at the economics of mental health, as a model for other federal agencies.

Creating a Common Nomenclature and Classification

This breakout session offered four suggestions regarding nomenclature:

1. Regardless of the nomenclature used, evaluation of progress toward the ADA's goals should occur at the interaction-with-environment ("handicap") level of analysis. For example, in the case of special education, the mind-set that "the problem is in the students" must be discarded and we must look toward physical or environmental issues. Positive measures of how accommodations can be achieved must be sought.
2. At the personal level ("disability"), positive measures of functional capacity are needed. This concept is important not just for rehabilitation purposes but also in evaluating who is covered under the ADA.
3. "Handicap" as a term is extremely controversial.
4. The ICIDH provides a classification system that other frameworks do not have.

Section III: Appendices

Appendix A: Conference Agenda

"Furthering the Goals of the ADA Through Disability Policy Research in the 1990s"

Hyatt Regency Washington on Capitol Hill
Washington, DC

Agenda

Monday, December 7, 1992

8:00 – 9:00 **Registration/Continental Breakfast**

9:00 – 9:30 **Welcome and Introduction**

Speakers: **Sandra Swift Parrino,** Chairperson, National Council on Disability

William E. McLaughlin, Acting Director, National Institute on Disability and Rehabilitation Research

9:30 – 10:00 **Session I**

Keynote Address—"Disability Research and Enforcement of the Americans with Disabilities Act"

Speaker: **John R. Dunne,** Assistant Attorney General, Department of Justice, Civil Rights Division

10:00 – 10:15 **Break**

10:15 – 11:45 **Session II (Part 1)**

Putting Research to Work for the Realization of the Goals of the ADA: The Perspective of the Community of Persons With Disabilities

Moderator: **A. Kent Waldrep,** National Council on Disability

Speakers: **Simi Litvak,** World Institute on Disability
Andrew Batavia, Abt Associates

Discussant: **Harlan Hahn,** University of Southern California

11:45 – 1:15 **Lunch (On Your Own)**

1:15 – 2:30 **Breakout Sessions**

- Equality of Opportunity—**Andrew Batavia,** Facilitator
- Full Participation—**Simi Litvak,** Facilitator
- Independent Living—**David Pfeiffer,** Facilitator
- Economic Self-Sufficiency—**Paul Leung,** Facilitator

Agenda

Monday, December 7, 1992 (cont'd)

2:30 – 3:45 **Session II (Part 2)**
Putting Research to Work for the Realization of the Goals of the ADA: The Perspective of Minorities and Other Underserved Populations

Moderator: **Frederick Bedell,** National Council on Disability

Speakers: **Paul Leung,** University of Illinois at Urbana-Champaign
Sylvia Walker, Howard University

Discussant: **Evelyn Davis,** Harlem Hospital

3:45 – 4:00 **Break**

4:00 – 5:00 **Reports from Breakout Sessions**

Moderator: **John A. Gannon,** National Council on Disability

Sessions:
- Equality of Opportunity—**Andrew Batavia,** Facilitator
- Full Participation—**Simi Litvak,** Facilitator
- Independent Living—**David Pfeiffer,** Facilitator
- Economic Self Sufficiency—**Paul Leung,** Facilitator

Tuesday, December 8, 1992

8:00 – 8:30 **Registration/Continental Breakfast**

8:30 – 9:45 **Session III**
Shaping an Interdisciplinary Field of Disability Studies Responsive to the Goals of the ADA

Moderator: **David Gray,** National Center for Medical Rehabilitation Research

Speakers:
- Economics—**David Dean,** University of Richmond
- Engineering—**Andrew Schoenberg,** University of Utah
- Health—**Gerben DeJong,** National Rehabilitation Hospital
- Social Policy—**Irving K. Zola,** Brandeis University
- Vocational Rehabilitation—**Susanne M. Bruyère,** Cornell University

Agenda

Tuesday, December 8, 1992 (cont'd)

9:45 – 10:00 **Break**

10:00 – 11:30 **Session IV**

Strategies for Adopting Common Nomenclature That Is Responsive to the Goals of the ADA: National and International Experiences

Moderator: **Gerry Hendershot,** National Center for Health Statistics

Speaker: **Michel Thuriaux,** World Health Organization
William Frey, Disability Research Systems, Inc.

Discussants: **Adele Furrie,** Post Censal Surveys Statistics, Canada
Donald Patrick, University of Washington

11:30 – 1:00 **Lunch (On Your Own)**

1:00 – 2:15 **Breakout Sessions**

- Issues Related to Special Populations—**Sylvia Walker,** Facilitator
- Emerging Issues—**Mitchell LaPlante,** Facilitator
- Building a Disability Study Discipline—**Irving Zola,** Facilitator
- Creating a Common Nomenclature & Classification—**Scott Campbell Brown,** Facilitator

2:15 – 3:45 **Session V (Part 1)**

Research Strategies for Statistics: Survey Data and Quantitative Research

Moderator: **Scott Campbell Brown,** Department of Education

Speakers: **Lois M. Verbrugge,** University of Michigan
Michelle Adler, Department of Health and Human Services

Discussants: **Mary Chamie,** United Nations
Michael Adams, Centers for Disease Control

3:45 – 4:00 **Break**

Agenda

Tuesday, December 8, 1992 (cont'd)

4:00 – 5:00 **Session V (Part 2)**
Research Strategies for Statistics: Survey Data and Qualitative Research

Moderator: **Mary Raether,** National Council on Disability

Speaker: **Carol Howland,** Baylor College of Medicine

Discussants: **Barbara Altman,** Agency for Health Care Policy Research
Nora Groce, Yale University

Wednesday, December 9, 1992

8:00 – 8:30 **Registration/Continental Breakfast**

8:30 – 10:00 **Session VI**
Research Strategies for Monitoring the ADA

Moderator: **Raymond Seltser,** Agency for Health Care Policy and Research

Speakers: **Mitchell LaPlante,** University of California at San Francisco

Discussants: **David Pfeiffer,** Suffolk University
Carolyn L. Feis, General Accounting Office
Jane West, Jane West & Associates

10:00 – 10:15 **Break**

10:15 – 11:30 **Reports from Breakout Sessions**

Moderator: **Harlan Hahn,** University of Southern California

Sessions:
- Issues Related to Special Populations—**Sylvia Walker,** Facilitator
- Emerging Issues—**Mitchell LaPlante,** Facilitator
- Building a Disability Study Discipline—**Irving Zola,** Facilitator
- Creating a Common Nomenclature & Classification—**Scott Campbell Brown,** Facilitator

Agenda

Wednesday, December 9, 1992 (cont'd)

11:30 – 1:00 **Lunch (On Your Own)**

1:00 – 2:30 **Session VII**
Furthering the Goals of the ADA: Disability Policy Research—Where Do We Go From Here?

Moderator: **Sandra Swift Parrino,** Chairperson, National Council on Disability

Speaker: **Irving Kenneth Zola,** Brandeis University

2:30 – 3:00 **Summary and Conclusions**

Speaker: **Sandra Swift Parrino,** Chairperson, National Council on Disability

Appendix B: Participant List

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Appendix D: The National Council on Disability: A Brief Description

The National Council on Disability: A Brief Description

Overview and Purpose

The National Council on Disability (NCD) is an independent federal agency led by 15 members appointed by the President of the United States and confirmed by the U.S. Senate. It was initially established in 1978 as an advisory board within the Department of Education (Public Law 95-602). The Rehabilitation Act Amendments of 1984 (Public Law 98-221) transformed NCD into an independent agency.

The overall purpose of NCD is to promote policies, programs, practices, and procedures that guarantee equal opportunity for all individuals with disabilities, regardless of the nature or severity of the disability; and to empower individuals with disabilities to achieve economic self-sufficiency, independent living, and inclusion and integration into all aspects of society.

Specific Duties

The current statutory mandate of NCD includes the following:

- Reviewing and evaluating, on a continuing basis, policies, programs, practices, and procedures concerning individuals with disabilities conducted or assisted by federal departments and agencies, including programs established or assisted under the Rehabilitation Act of 1973, as amended, or under the Developmental Disabilities Assistance and Bill of Rights Act; and all statutes and regulations pertaining to federal programs that assist such individuals with disabilities in order to assess the effectiveness of such policies, programs, practices, procedures, statutes, and regulations in meeting the needs of individuals with disabilities.
- Reviewing and evaluating, on a continuing basis, new and emerging disability policy issues affecting individuals with disabilities at the federal, state, and local levels, and in the private sector, including the need for and coordination of adult services, access to personal assistance services, school reform efforts and the impact of such efforts on individuals with disabilities, access for health care, and policies that operate as disincentives for the individuals to seek and retain employment.
- Making recommendations to the President, the Congress, the Secretary of Education, the Director of NIDRR, and other officials of federal agencies, concerning ways to better promote equal opportunity, economic self-sufficiency, independent living, and inclusion and integration into all aspects of society for Americans with disabilities.
- Providing the Congress, on a continuing basis, advice, recommendations, legislative proposals, and any additional information that the Council or the Congress deems appropriate.
- Gathering information about the implementation, effectiveness, and impact of the ADA of 1990 (42 U.S.C. 12101 et seq.).
- Advising the President, the Congress, the Commissioner of the Rehabilitation Services Administration, the Assistant Secretary for Special Education and Rehabilitative Services within the Department of Education, and the Director of NIDRR on the development of the programs to be carried out under the Rehabilitation Act of 1973, as amended.
- Providing advice to the Commissioner with respect to the policies of and conduct of the Rehabilitation Services Administration.
- Making recommendations to the Director of NIDRR on ways to improve research, service, administration, and the collection, dissemination, and implementation of research findings affecting persons with disabilities.

- Providing advice regarding priorities for the activities of the Interagency Disability Coordinating Council and reviewing the recommendations of such Council for legislative and administrative changes to ensure that such recommendations are consistent with the purposes of the Council to promote the full integration, independence, and productivity of individuals with disabilities.
- Preparing and submitting to the President and the Congress a report entitled *National Disability Policy: A Progress Report* on an annual basis.
- Preparing and submitting to the Congress and the President a report containing a summary of the activities and accomplishments of the Council on an annual basis.

Population Served and Current Activities

Although many government agencies deal with issues and programs affecting people with disabilities, NCD is the only federal agency charged with addressing, analyzing, and making recommendations on issues of public policy that affect people with disabilities, regardless of age, disability type, perceived employment potential, economic need, specific functional ability, status as a veteran, or other individual circumstance. NCD recognizes its unique opportunity to facilitate independent living, community integration, and employment opportunities for people with disabilities by ensuring an informed and coordinated approach to addressing the concerns of persons with disabilities and eliminating barriers to their active participation in community and family life.

NCD plays a major role in developing disability policy in America. In fact, it was the Council that originally proposed what eventually became the Americans with Disabilities Act of 1990. Our present list of key issues includes personal assistance services, health care reform, the inclusion of students with disabilities in high-quality programs in typical neighborhood schools, equal employment opportunity, community housing, monitoring the implementation of the ADA, improving assistive technology, and ensuring that persons with disabilities who are members of minority groups fully participate in society.

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